# SYMPTOM EXPERIENCE AND FATIGUE MANAGEMENT AMONG LEUKEMIC CHILDREN RECEIVING CHEMOTHERAPY

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Thesis entitled

## SYMPTOM EXPERIENCE AND FATIGUE MANAGEMENT AMONG LEUKEMIC CHILDREN RECEIVING CHEMOTHERAPY

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Nopparat Prajimtis

## SYMPTOM EXPERIENCE AND FATIGUE MANAGEMENT AMONG LEUKEMIC CHILDREN RECEIVING CHEMOTHERAPY

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#### ABSTRACT

Inevitably, fatigue is the most frequently experienced symptom in leukemic children receiving chemotherapy. This descriptive research aims to explore the fatigue experience, fatigue outcome interference with functional status, and fatigue management strategies in leukemic children receiving chemotherapy. The conceptual framework of this study is based on revised symptom management conceptual model (Dodd et al., 2001). The sample in this study comprised 50 leukemic children between 7-12 years of age, who were receiving chemotherapy at the in-patient department of Ramathibodi Hospital, King Chulalongkorn Memorial Hospital, and Queen Sirikit National Institute of Child Health using purposive sampling from March to September 2003. The questionnaires used to collect data were Characteristics and Clinical data Form, Fatigue Interview Form and Fatigue Management Strategies for Leukemic Children Receiving Chemotherapy Form. Data analysis employed descriptive statistics.

The results of this study showed that 72% of leukemic children reported fatigue experience as physical changes such as headache, dizziness, etc. Severity of fatigue was in moderate level (Mean=5.52,S.D.=2.07). The leukemic children reported the highest feeling of fatigue in the afternoon, 62%. Additionally, 80% of leukemic children reported on causes of fatigue resulting from chemotherapy. The most physical response reported by leukemic children was muscle fatigue and pain, 86%. The psychological and emotional responses resulting from fatigue were anxiety and fear (70%). The behavioral response reported most was drowsiness and low spirits, 74%. Fatigue outcomes interfere with functional status at moderate level. Sleep was the best management strategy chosen by leukemic children to cope with fatigue 100% and was found to be the most effective strategy.

The results of this study suggest that nurses should assess fatigue and fatigue response and select appropriate management strategies to relieve fatigue in each leukemic child so that, the patient could manage fatigue effectively, thus promoting quality of life.

#### KEY WORDS: FATIGUE / SYMPTOM EXPERIENCE / FATIGUE MANAGEMENT / LEUKEMIA / CHEMOTHERAPY 85 pp. ISBN 974-04-5000-8

ประสบการณ์มีอาการและการจัดการกับความอ่อนล้าในผู้ป่วยเด็ก โรคมะเร็งเม็ดเลือดขาวที่ได้รับการรักษาด้วยยา เกมีบำบัด (SYMPTOM EXPERIENCE AND FATIGUE MANAGEMENT AMONG LEUKEMIC CHILDREN RECEIVING CHEMOTHERAPY)

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### บทคัดย่อ

ความอ่อนด้าเป็นอาการที่พบได้เสมอ และเป็นสิ่งที่หลีกเลี่ยงไม่ได้ ในผู้ป่วยเด็กโรคมะเร็งเม็ดเลือด งาวที่ได้รับการรักษาด้วยยาเคมีบำบัด การวิจัยครั้งนี้เป็นการวิจัยเชิงบรรยาย เพื่อสึกษาประสบการณ์ความอ่อนล้า ผลของความอ่อนล้าที่รบกวนภาวะ การทำหน้าที่ตามการรับรู้ของผู้ป่วยเด็ก และกลวิธีการจัดการกับความอ่อนล้า ในผู้ป่วยเด็กโรคมะเร็งเม็ดเลือดขาวด้วยยาเคมีบำบัด กรอบแนวคิดที่ใช้ในงานวิจัยนี้ คือ แบบจำลองการจัดการ กับอาการของดอดและคณะ กลุ่มตัวอย่างเป็นผู้ป่วยเด็กโรคมะเร็งเม็ดเลือดขาว อายุระหว่าง 7-12 ปีจำนวน 50 คน เข้ารับการรักษาในโรงพยาบาลด้วยยาเคมีบำบัดที่หอผู้ป่วยในโรงพยาบาลรามาธิบดี, โรงพยาบาล จุฬาลงกรณ์และสถาบันสุขภาพเด็กแห่งชาติมหาราชินี จังหวัดกรุงเทพมหานคร โดยเลือกกลุ่มตัวอย่างตาม คุณสมบัติที่กำหนด ระยะเวลาในการเก็บข้อมูลระหว่างเดือนมีนาคมถึงกันยายน 2546 เก็บข้อมูลโดยใช้แบบ บันทึกข้อมูลทั่วไป, แบบสัมภาษณ์ความอ่อนล้าและแบบสัมภาษณ์กลวิธีการจัดการกับความอ่อนล้าในผู้ป่วยเด็ก โรคมะเร็งเม็ดเลือดขาวที่ได้รับการรักษาด้วยยาเคมีบำบัด และวิเคราะห์ข้อมูลด้วยสถิติบรยาย

ผลการวิจัขพบว่า ลักษณะของความอ่อนล้ำตามการรับรู้ของผู้ป่วย ส่วนใหญ่เป็นการรับรู้เกี่ยวกับอาการ เปลี่ยนแปลงทางร่างกาย เช่น ปวดศีรษะ เวียนศีรษะ เป็นต้นร้อยละ 72 ระดับความอ่อนล้าของกลุ่มตัวอย่างอยู่ใน ระดับปานกลาง (Mean=5.52,S.D.=2.07) ช่วงเวลาที่ผู้ป่วยเด็กรู้สึกว่ามีระดับความอ่อนล้ำมากที่สุด คือ ช่วงเวลา กลางวันร้อยละ 62 ซึ่งสาเหตุส่วนใหญ่ที่ทำให้เกิดความอ่อนล้า คือ การที่ได้รับการรักษาด้วยขาเคมีบำบัด ร้อยละ 80 การตอบสนองต่อความอ่อนล้าทางด้านร่างกาย ผู้ป่วยเด็กโรคมะเร็งเม็ดเลือดขาวระบุมากที่สุด คือ อาการปวดเมื่อยเนื้อเมื่อยดัว ร้อยละ 86 การตอบสนองต่อความอ่อนล้าทางด้านจิตใจและอารมณ์ ผู้ป่วยเด็ก โรคมะเร็งเม็ดเลือดขาวระบุมากที่สุด คือ อาการวิตกกังวลหรือกลัวในสิ่งที่จะเกิดขึ้นกับตนเอง ร้อยละ 70 การตอบสนองต่อความอ่อนล้าทางด้านพฤติกรรม ผู้ป่วยเด็กโรคมะเร็งเม็ดเลือดขาวระบุมากที่สุด คือ มีอาการ เชื่องซึม เช่น เหงาหงอย ไม่พูดไม่จา ไม่เบิกบาน ร้อยละ 74 ผลของความอ่อนล้าที่มีต่อการรบกวนภาวะการทำ หน้าที่ของร่างกายในระดับปานกลาง วิธีการจัดการที่ผู้ป่วยเด็กโรคมะเร็งเม็ดเลือดขาวนำมาใช้ในการจัดการกับ ความอ่อนล้าที่เกิดขึ้นมากที่สุด คือ การนอนหลับ ร้อยละ 100 วิธีการจัดการที่มีประสิทธิภาพมากที่สุด คือ การ นอนหลับ

จากผลการศึกษาเสนอแนะว่าพขาบาลควรมีความตระหนักในการประเมินความอ่อนล้าและการ ตอบสนองที่เกิดจากความอ่อนล้าและเลือกวิธีการจัดการกับความอ่อนล้าให้มีความเหมาะสมสำหรับผู้ป่วยแต่ละ คนเพื่อให้ผู้ป่วยจัดการกับความอ่อนล้าที่เกิดขึ้นได้อย่างมีประสิทธิภาพ และมีคุณภาพชีวิตที่ดี

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# CHAPTER 1 INTRODUCTION

#### **Background and Rationale**

Leukemia is the most common form of childhood cancer. The rate was found 30% among the total cases with the ratio of 3.7/100,000 Thai children (Kulpong, 2540: 21). Advances in diagnosis and treatment have increased the survival of all children with leukemia, and 80 percent of the cases especially those with acute lymphoblastic leukemia can be cured in 5 years with effective chemotherapy and irradiation (American Cancer Society, 1998 cited in Hasse, Mauer, & Reaman, 1998: 822). Currently, chemotherapy is one of the most effective treatment modalities for leukemia. During the treatment, leukemic children may have suffered from the disease and the side effects of chemotherapy. These side effects include nausea, vomiting, anorexia, stomatitis, diarrhea, alopecia, and fatigue (Kulpong, 2540: 19; Pritsanapanurungsie, 2001: 98; Hockenberry-Eaton et al., 1998: 174). Fatigue is the most frequently experienced symptom and unavoidable (Pritsanapanurungsie, 2001: 98; Aistars, 1987: 25; Blesch, et al., 1991: 81; Hockenberry-Eaton & Hinds, 2000: 261). The incidence of fatigue from cancer therapies was 70 % among patients receiving chemotherapy (Hockenberry-Eaton & Hinds, 2000: 261). Fatigue is described as a human response to cancer and treatment that may be characterized by subjective feelings of weakness, exhaustion, and lack of energy resulting from prolonged exertion or stress shown by physical and mental. Fatigue has been identified as a phenomenon that is characterized by increased feelings of discomfort and decreased functional status. Moreover, fatigue has an impact on self-care abilities, self-concept, employment, social relationships, and individuals' quality of life (Pritsanapanurungsie, 2001:1; Ferrell et al., 1996: 1542-1545; Skalla & Lacasse, 1992:1537). In childhood cancer, fatigue is a significant concern because these children are undergoing normal physiological and developmental changes. Physiologically, fatigue decreases muscle contractility especially among those school age children during their rapid physical and developmental changes. It causes

reduced motion and functions including declined activities of daily living (Hockenberry–Eaton et al., 1998:176-177). The decreased ability of physical movement causes the lack of stimulation of nervous and muscle functioning systems (Winningham, 1994: 26). This long period of such condition may interrupt learning opportunity as well as age specific developmental changes. In socio-psychological aspect, fatigue causes the loss of self control and self care ability to perform activities of daily living and desired activities. Children at this age are unable bearing the feeling of decreased self-control power while become more dependent to others, loss of self-esteem, become inferior and hurt for having poor health, and feel reduced self-value. Their responses include mental stress and depress, disengaged, upset, and oppressed (Visespanich, 1998: 2; Hinds et al., 1999a: 282).

Kulsu (2544) studied in 18 leukemic children receiving chemotherapy aged 7-15 admitted in pediatric ward at Maharaj Nakorn Chiang Mai Hospital in Thailand. The result showed the highest rising fatigue level was found on the second day of chemotherapy.

Fatigue severity may change during chemotherapy (Piper et al., 1987: 20) which varies from one case to another that effects physiological, psychological, and emotional responses. The effect of fatigue on such response had been studied. It was found physiologically that there has been an increase of energy use from utilizing stored energy and hence causing fatigue and exhaust, delayed movement, and depress (Aistars, 1987: 26; Hart et al., 1990: 969; Larson et al., 1993:473). Other findings included numbness of finger and toes, eyes pain, sometimes experiencing headache and dizziness (Varricchio, 1985, cited in Kongthong, 2544: 2). Psychological and emotional response includes easily loss of temper,swing mood (Hart et al., 1990: 2) and lethargic. Such physiological and psychological responses effect the body function both physically and mentally (Aistars, 1987: 25-26; Hinds et al., 1999a: 282; 1999b: 37-45; Hockenberry-Eaton et al., 1998: 172-182).

Regarding fatigue management strategies, Hinds et al. (1999a: 281-282) had conducted a study among 14 children aged 7 - 12 years who had cancer. The results indicated that alleviating factors in patient's perspectives were taking naps, having visitors, and doing fun activities. Furthermore, fatigue management strategies in adult patients were studied among 30 cases with breast cancer receiving chemotherapy by

Pritsanapanurungsie (Pritsanapanurungsie, 2001: 97). The results suggested that selfcare practice to manage fatigue was lying down for rest which effects almost complete relief. Saejew (2001: 67-68) had studied in 60 patients with head and neck cancer and reported that the most frequent practiced self-care to manage fatigue were lying down and sleeping, while stopping received radiation therapy was the most effective strategy.

Fatigue is a distress symptom, with physical, psychological and emotional dimensions that children experience while being treated for cancer (Hinds et al., 1999a: 282; 1999b: 37-45; Hockenberry-Eaton et al., 1998: 172-182). The underlying pathophysiology of fatigue is complex and difficult to understand and health professional had a little to offer to treat fatigue. Fatigue is the symptom that remains difficult to manage and lately has been exacerbated with the increases use of fatigue inducing multimodal treatments. The phenomenon of fatigue in leukemic children receiving chemotherapy is a subjective sensation resulting from physical, psychological and sociological factors and occurs in different conditions. As stated previously, the phenomenon of fatigue in 7 - 12 year-old patients with cancer has not well studied. In Thailand, very few studies on the symptoms of fatigue were found. The lack of research in this issue has therefore become interesting for further studies. The purpose of this study is to describe fatigue experience, fatigue outcomes interference with functional status and fatigue management strategies in leukemic children receiving chemotherapy. This study facilitates nurses to understand the subjective sensations for the perception of fatigue, severity, etiology, outcomes and management strategies for fatigue. The result of this study would be useful for nurses to help analyze, evaluate and plan to solve the problems experienced by the patients and to improve the quality of nursing intervention.

#### **Conceptual framework**

The conceptual framework of this study was based on revised symptom management conceptual model (see figure I) (Dodd et al., 2001: 668-676). In the revised model the recognized domains of nursing science, person, health/illness and environment are contextual variables influencing all three dimensions of the model, i.e. symptom experience, management strategies and outcomes.

#### Person domain

Person variables, such as demographic, psychological, sociological and physiological are intrinsic to the way an individual views and responds to the symptom experience. Developmental variables include the level of development or maturation of an individual.

#### Health and illness domain

The domain of health and illness comprises variables unique to the health or illness status of an individual, which includes risk factors, injuries, or disabilities. Health and illness domain has direct and indirect effects on symptom experience, management and outcomes.

#### **Environment domain**

The environment refers to the aggregate of conditions or the context within which a symptom occurs; that is, it includes physical, social and cultural variables. The physical environment may encompass home, work and hospital. The social environment includes one's social support network and interpersonal relationships. Cultural aspects of the environment are those beliefs, values and practices that are unique to one's identified ethnic, racial, or religious group.

In summary, the three domains of nursing science (person, health/illness and environment) affect and modify all three dimensions of the symptom management model.

#### Symptom experience

The symptom experience includes individual's perception of a symptom, evaluation of it and response to such symptom.

#### **Perception of symptoms**

Perception of symptoms refers to whether an individual notices a change from the way he or she usually feels or behaves.

#### **Evaluation of symptoms**

Evaluation of symptoms entails a complex set of a factor that characterize the symptom experience, including its severity, location, temporal nature, frequency and affective impact.

#### **Response to symptom**

Response to symptom includes physiologic, psychological, sociocultural and behavioral components. One or more of any of these responses may be seen within a single symptom.

Understanding the interaction of these components of the symptom experience is essential if symptoms are effectively managed.

#### Symptom management strategies

Management begins with assessment of the symptom experience from individual's perspective. Symptom management is a dynamic process, often requiring changes in strategies over time or in response to acceptance or lack of acceptance of the strategies devised. The revised model includes the specifications of what, when, where, why, how much (Intervention dose), to whom (recipient of intervention) and how (delivered). Researchers and clinicians consider these questions as they design, develop and prescribe symptom management strategies.

#### Symptom outcomes

Symptom outcomes emerge from symptom management strategies as well as from the symptom experience. The symptom outcomes dimension focuses on eight factors including functional status, self-care, costs, quality of life, morbidity & comorbidity, mortality, emotional status and symptom status.



Figure 1 The revised symptom management conceptual model (Dodd et al., 2001: 668-676).

This study describes fatigue experience, fatigue outcomes interference with functional status and fatigue management strategies in leukemic children receiving chemotherapy. This study provides an opportunity to patients to explore symptom experience, and to learn about the disease as well as to participate in fatigue management. Fatigue is a severe symptom in cancer patients especially the symptom and feeling of leukemic children who have fatigue during chemotherapy which differs from one person to another but with interrelation. The researcher had studied fatigue experience from patients' perspective covering all 3 dimensions as the following.

1. **Perception of symptoms:** It refers to the perceived fatigue of leukemic children who recognize such feeling and try to collect such feeling, and then interpret the fatigue that caused from chemotherapy.

2. **Evaluation of symptoms:** It refers to the judgment done by patients about fatigue experience and evaluates it in terms of severity, duration and etiology of fatigue from chemotherapy.

3. **Response to symptoms:** It refers to the response of patients to the fatigue which includes physiological, psychological, and behavioral components.

Symptom outcomes mean the effect of fatigue experience that obstructs functional status of the body. Functional status means maintaining one's ability to perform activities at maximum level without depending on others, i.e. activities of daily living, walking and physical movement, etc. The review of literature suggested that fatigue affects reduced functional status of the body. The researcher had studied the effect of fatigue experience in interfering of functional status of the body since school age children had undergone the rapid physical and developmental changes. Fatigue causes delayed movement in the child patients and impaired ability to perform normal activities even their activities of daily living (Hockenberry–Eaton et al., 1998: 176-177). Reduced movement ability may affect the lack of stimulation of nervous system and muscles resulting in its less functional status (Winningham, 1994: 26). The long duration of reduced body movement leads to the lack of opportunity to learn and thus obstructing age appropriate developmental changes, followed by psychological and emotional problems.

Symptom management strategies begin with the assessment of fatigue experience from patients' perspective; evaluation of fatigue; and fatigue outcomes. The leukemic children search their own appropriate management method to control or relieve fatigue. Symptom management strategies refer to strategies used to manage fatigue. The goal of fatigue management is to overt or delay negative outcomes though biomedical, professional, and self-care strategies by controlling contributing factors of fatigue with medication. Symptom management strategy is a dynamic process, often requiring changes in strategies over times or in response to a patient's acceptance (or no acceptance) of the strategy. In this part the researcher had studied about the strategies used by the patients to manage their fatigue, and how they evaluate the effectiveness of management method. The effectiveness of management strategies here means the strategies used by the child patients to reduce the fatigue that is judged by the patients' feeling.

#### **Research questions**

- 1. What were the nature and extent of fatigue experience among leukemic children receiving chemotherapy?
- 2. How did the fatigue outcomes interfere functional status of those leukemic children receiving chemotherapy?
- 3. What were the fatigue management strategies for leukemic children receiving chemotherapy?
- 4. How was the effectiveness of fatigue management strategies perceived by leukemic children receiving chemotherapy?

#### **Research objectives**

- 1. To describe fatigue experience in leukemic children receiving chemotherapy.
- 2. To describe fatigue outcomes interference with functional status in leukemic children receiving chemotherapy.
- 3. To describe fatigue management strategies used by leukemic children receiving chemotherapy.

4. To determine the effectiveness of fatigue management strategies perceived by leukemic children receiving chemotherapy.

#### Scope of the study

This descriptive study aims to describe the fatigue experience, fatigue outcomes interference with functional status, and fatigue management strategies in leukemic children receiving chemotherapy. The samples are children with leukemia who admitted the pediatric department in Ramathibodi Hospital, King Chulalongkorn Memorial Hospital, and Queen Sirikit National Institute of Child Health, during March-September, 2003.

#### **Expected outcomes and benefits**

The results of this study can serve as the basis:

1. For Nurses to understand that fatigue is a subjective experience that varies in severity, etiology, outcomes and management strategies for each leukemic child receiving chemotherapy. This knowledge would help nurses plan appropriate intervention for this patient population.

2. For nurse educator to incorporate the concept of fatigue into nursing curriculum for nursing students at all levels.

3. For nurse researcher to conducting further research related to fatigue experience and fatigue management among other pediatric oncology patients and other pediatric patients.

#### **Definition of Terms**

**Fatigue** is a subjective experience. It is a feeling of weariness, tiredness, lack of energy, exhaustion, lethargy or malaise occurring during receiving chemotherapy.

- **Symptom experience** refers to symptoms and feeling of leukemic children receiving chemotherapy defined as patient's perception of fatigue, evaluation of fatigue and response to such fatigue during the feeling of fatigue. It refers to individual's feeling about changes in his/her body. It is measured by the Fatigue Interview Form developed by the researcher based on Revised Symptom Management

Conceptual Model (Dodd et al., 2001: 668-676). Symptom experience consists of three dimensions as the following

- **Perception of fatigue** refers to whether an individual notices a change from the way he or she usually have fatigue feelings or behavior during receiving chemotherapy.

- Evaluation of fatigue refers to the judgment of patients about fatigue experience for evaluation of fatigue, including its severity, duration and etiology of fatigue.

- **Response to fatigue** refers to physiological, psychological and behavioral change of patients toward fatigue.

**Fatigue outcomes interference with functional status** refers to the fatigue experience of discomfort interfering functional status of the patients and lead to inability to perform activities such as activities of daily living, walking, moving, playing and doting fun activities. Fatigue assessment form was modified by the researcher from the Revised Piper Fatigue Scale (Piper et al., 1998) as Numeric Rating Scale in which lower score means less interference, and higher score means high interference.

**Fatigue management strategies** refers to activities that patients initiate and perform to relieve fatigue. It was measured by the Fatigue Management Strategies in Leukemic Children Receiving Chemotherapy From. Interview form developed by the researcher based on Revised Symptom Management Conceptual Model (Dodd et al., 2001: 668-676).

**Effectiveness of fatigue management strategies** refers to the outcome of management strategies the patients used to manage fatigue, measured by The Fatigue Management Strategies in Leukemic Children Receiving Chemotherapy From. Interview form developed by the researcher is based on Revised Symptom Management Conceptual Model (Dodd et al., 2001: 668-676). Lower score means less effective management strategies, and higher score means more effective management strategies.

# CHAPTER 2 LITERATURE REVIEW

The aim of this study was to describe the fatigue experience, fatigue outcomes interference with functional status and fatigue management strategies in leukemic children receiving chemotherapy. The review of related literature is presented in 7 topics as follows:

- 1. Childhood leukemia
- 2. Chemotherapy for leukemia
- 3. Self care agency for school-age children
- 4. Fatigue in childhood cancer
  - Definition of fatigue
  - Incidence of fatigue
  - Factors related to fatigue
- 5. Fatigue experience
  - Perception of fatigue
  - Evaluation of fatigue
  - Response to fatigue
- 6. Fatigue outcomes interference with functional status
- 7. Fatigue management strategies

#### **Childhood leukemia**

Leukemia is the most common childhood malignancy. Annually, leukemia occurs in 4 out of 100,000 children younger than 15 years of age (Poplack, 1997 cited in Bowden, Dickey, & Greenberg, 1998: 1473). Leukemia is a complex collection of diseases that was first described by Virchow in 1845 that it is a condition in which the relationship between red and colorless corpuscles was the reverse of normal. He coined the term "white blood". The two major classifications of leukemia are acute and chronic. These two types of leukemia are similar in that they are the products of

dysfunctional bone marrow, but they differ dramatically in disease presentation, treatment, and prognosis. The cell line of origin can characterize acute and chronic leukemia as myeloid or lymphoid. Acute lymphoblastic leukemia (ALL) accounts for approximately 75% of childhood leukemia, acute non-lymphoblastic leukemia (ANLL) approximately 20% and chronic myelocytic leukemia (CML) approximately 5% (Kulpong, 2540: 21).

Acute lymphoblastic leukemia refers to the extreme proliferation of immature lymphocytes. These immature lymphocytes are referred to as blast cells. The French-American-British (FAB) coorperative group has established a classification system for acute leukemia based on the form, structure, and chemistry (morphology) of the blast cells. Lymphoblasts occur in three types: L1, L2, and L3. The cell type most commonly found in ALL is L1, which is seen in 85% of children with ALL, and has the best prognosis (Kulpong, 2540: 25-28; Poplack, 1997 cited by Bowden, Dickey, & Greenberg, 1998: 1473).

Acute non-lymphoblastic leukemia or acute myelogeneous leukemia, this transformation occurs on a non-lymphocytic cell line. ANLL develops in the bone marrow. The malignant clone causes a proliferation of immature, relatively undifferentiated cells that replace healthy bone marrow elements. The immature cells accumulate in the marrow and in extramedullary sites, causing bone marrow failure (Kulpong, 2540: 72-76; Kalwinsky et al., 1990 cited by Bowden, Dickey, & Greenberg, 1998: 1479). The FAB system is the standard classification used to describe the seven subtypes of ANLL: M1, M2, M3, M4, M5, M6, and M7 which constitute 10-20% of leukemia in children. The subtypes of ANLL are not clearly related to prognosis, as is the cause with ALL (Whaley & Wong, 1999: 1727).

In all types of leukemia, the proliferating cells depress bone marrow production of the formed elements of the blood by competing for and depriving the normal cells of the essential nutrients for metabolism. The three main consequences are (1) anemia from decrease erythrocytes, (2) infection from neutropenia, and (3) bleeding from decreased platelet production. The invasion of the bone marrow with leukemia cells gradually causes a weakening of the bone and a tendency toward fractures. As leukemic cells invade the periosteum, increasing pressure causes severe pain.

The most frequent presenting signs and symptoms of leukemia are result of infiltration of the bone marrow. These include fever, pallor, fatigue, anorexia, hemorrhage (usually petechiae), and bone and joint pain. The spleen, liver, and lymp glands demonstrate marked infiltration, enlargement, and eventually fibrosis. Hepatosplenomegaly is typically more common than lymphadenopathy (Whaley & Wong, 1999: 1733).

#### **Chemotherapy for leukemia**

Chemotherapy may be the primary form of treatment, or it may be used as an adjunct to surgery and/or radiotherapy. Although several drugs with antineoplastic capabilities have been found effective in treating different forms of cancer, the remarkable survival rates have been the result of improved combination-drug regimen. Combining drugs allows for optimum cell cycle destruction with minimum toxic effects and decreased resistance by the cancer cells to the agent (Whaley & Wong, 1999: 1709; Alcoser & Rodgers, 2003: 103).

Chemotherapeutic agents are pharmacologically classified into six categories: Alkylating agents, Antitumor antibiotics, Antimetabolites, Plant alkaloids, Hormones and corticosteroids, and Miscellaneous agents (Whaley & Wong, 1999: 1709).

Treatment for children with ALL is devided into stage: remission induction, consolidation or intensification, and maintenance or continuation therapy, with CNS sanctuary therapy generally provided in each stage (Kulpong, 2540: 48-53; Colby-Graham & Chordas, 2003: 90).

The common regimens used for adjuvant chemotherapy of ANLL are as follows: (1) Induction (2) Post remission therapy and (3) CNS prophylaxis (Kulpong, 2540: 83-85; Colby-Graham & Chordas, 2003: 93).

Advances in treatment have resulted in therapies that, although beneficial, have short- and long-term side effects that impact on the individual's physical and psychosocial well being. Currently, chemotherapy is one of the most effective treatment modalities for leukemia. However, chemotherapeutic agents cause many side effects include nausea, vomiting, anorexia, stomatitis, diarrhea, alopecia, and fatigue (Kulpong, 2540: 19; Pritsanapanurungsie, 2001: 98; Hockenberry-Eaton et al., 1998: 174). Fatigue is unavoidable and the most frequently experienced symptom

during receiving chemotherapy (Pritsanapanurungsie, 2001: 98; Aistars, 1987: 25; Blesch et al., 1991: 81; Hockenberry-Eaton & Hinds, 2000: 261). People with cancer have identified fatigue as a major troubling symptom and the primary cause of distress in their lives as they contend with their illness and its treatment (Holley, 2000: 1425). Experiences of fatigue founded are lack of energy, weakness, and drowsiness. Fatigue has an impact on individual's physical and psychological well being.

#### Self care agency of school-age children

In this study, fatigue experience, fatigue outcomes interference with functional status and fatigue management strategies were studied among 7-12 years old leukemic children receiving chemotherapy. The literature review suggested that school-aged children are more capable of taking care of themselves. Children will learn self-care skills and improve what they have learned earlier. School-aged children are children aged 6-12 years. According to health condition perception of school-age children, based on Piaget's stages of cognitive development, children aged 7-11 years are in the period of concrete operations. They are able to think abstractly and reasonably, and to handle and classify problems (Velasco-Whetsell et al., 2002: 83). They are capable of concrete problem solving, and have ability to simultaneously distinguish thoughts in many aspects. The backward thinking is also possible. At this age, children can identify causes of illness correctly. They learn and understand that treatment can make illness better (Lamchang & Chotibang, 2544: 8). At 11 years or older, they have the ability of abstract problem solving. They can make anticipations. Their intellectuality develops to the stage that they can solve problem logically and systematically from their own knowledge or experiences.

#### Fatigue in childhood cancer

#### **Definition of fatigue**

Fatigue is a complex personal feeling varies among individuals. The literature review suggested different meanings of fatigue. Fatigue is a condition characterized by subjective feelings of generalized weariness, weakness, exhaustion, and lack of energy resulting from prolonged stress that is directly or indirectly attributable to disease process. The outcome is an impaired functional status, which ultimately has an impact on quality of life (Aistars, 1987: 25).

Piper et al. (1987: 678) cited that fatigue is the perception of individual who experiences extremely tiredness and exhaustion resulted from changes within the body. Such fatigue causes different degree and duration of unhappiness. Fatigue becomes stronger and remains and cannot be treated by sleeping. Fatigue affects physically and mentally as well as thought on cancer patients. Individual can perceive fatigue in 4 aspects: behavioral or severity; opinion or attitude; feelings; and intellectual or emotional.

Fatigue has been described as a symptom or manifestation of many diseases. Fatigue as a self-recognized phenomenon is subjective in nature apparent only to the affected individual and is not directly observable by another; instead, symptoms become known only to report of the person being assessed. Fatigue is experienced as a feeling of weakness, tiredness, or lack of energy that varies in degree, frequency, and duration (Jacobs & Piper, 1996: 1193).

Fatigue affects both psychological and physical functioning. The nature of fatigue includes multiple somatic complaints, excessive sleepiness, low energy, decreased appetite, loss of interest or pleasure in usual activities, loneliness, social isolation, and feelings of unhappiness (Hockenberry -Eaton et al., 1998: 173-174).

Penkamol Kulsu (2544: 14) stated that fatigue in cancer patients is a perception of individual shown by physical and psychological tiredness that causes impaired functional status.

The review of literature above can be concluded that fatigue is a feeling of individual observed by physical and psychological expression that affects impaired functional status and the quality of life of the patients.

#### **Incidence of fatigue**

The incidence of fatigue in child patients with leukemia is not clearly known. Wolfe et al. (2000, cited in Kulsu 2544: 23) had interviewed 65 cases of mothers of the patients and revealed that fatigue is the most common symptom found but received least treatment with low level of success.Collins et al. (2000, cited in Kulsu 2544: 24) had studied the fatigue symptom among 160 cases of 10 - 18 year-old-child patients with cancer and found that, among 22 symptoms, fatigue or weakness was reported as high as 49.7 percent and frequently occurred for 40.9 percent. Fatigue can be found in any cancer but most obvious among the child patients with cancer at lymphatic glands and brain cancers. Fatigue in leukemic children was found 43.8 percent, secondly most found from the pain.

Hockenberry-Eaton et al. (1998: 172-182) had carried out a study on fatigue among 29 cases of child patients, 14 cases aged 7-15 and 15 cases aged 13-16, who had leukemia, cancer at lymphatic glands and severe malignancy. The result suggested that most of the child patients reported having fatigue that relates to the treatment especially chemotherapy.

Hinds et al. (1999a: 281-286) conducted interviews with 31 cases of mothers of child patients with leukemia cancer at lymphatic glands and severe malignancy. He found that fatigue in child patients with cancers was most reported by their mothers. They said such fatigue shown as tiredness from doing activities such as walking and talking, and the fatigue remained although having full rest.

It can be seen that fatigue is the symptom occurs from, during or after chemotherapy. Fatigue is commonly found in child patients with cancer, and at high rate of incidence.

#### Factors related to fatigue

The review of literature presented a number of studies about factors related to fatigue as in the followings.

Hinds et al. (1999a: 281-286) explained that factors related to an increased/ reduced level of fatigue among children are of 3 aspects: 1) environmental factor – noise in the hospital, being awaken while sleeping; 2) individual factor or behavior – interrupted sleeping, performing various activities, emotional expression of guardians, change in social status; and 3) treatment or treatment related factor – side effect of chemotherapy. Factors related to reduced level of fatigue include: environmental factor – no disturbance during sleeping, having enough daytime sleeping; individual factor or behavior – no disturbance during sleeping, meeting with familiar people, engagement in social activities; and treatment or related treatment factor – taking sleeping aid pill and nausea pill, and receiving blood.

Similarly, the study of Kulsu (2544: 54-61) found that factors reported by child patients related to increased fatigue were noisy, smell, light, and being awaken during sleeping, change of sleeping pattern, inability to perform desired activities, loss of appetite, side effect of chemotherapy, and suffering from pain due to treatment. Whereas factors related to reduced fatigue include no disturbance from noise, smell, lights, being awaken, normal sleeping pattern, ability to perform desired activities, appetizing, being visited by sibling, no side effect from chemotherapy, and no suffering from pain due to chemotherapy.

Among adult patients with cancer, factors related to fatigue are due to chemotherapy such as pain, duration of illness, including emotional status caused by suffering from side effect, emotional change, weight loss, and reduced level of white blood cell resulting in increased fatigue. Others include loss of appetite and insomnia (Pritsanapanurungsie, 2001: 98).

#### **Fatigue experience**

#### **Perception of fatigue**

The concept related to perception of fatigue from the model of fatigue management explained that the child patients with leukemia perceived fatigue from their feelings and using intellectual to collect such feeling and interpret it from receiving chemotherapy. Such fatigue is personal feeling influenced by 1) person variables – an important internal factor, if it is existed prior to the symptom, it influence the perception of symptom of individual, i.e. demographic characteristics such as sex, education, race, marital status, and economic status, psychological characteristic including personality, and ability in thinking and motivating, and sociological characteristic like family, culture, religious; physiological characteristic; 2) health / illness factors – reflecting acute deviation or chronic caused by the disease, and 3) environmental factor - phenomenon and background in a situation perceived.

These all 3 are co-factors influencing the perception of individual (Dodd et al., 2001: 668-676). According to the literature review regarding the concept of fatigue, Piper et al. (1987: 17-23) explained that individual can perceive fatigue in 4 dimensions, i.e. behavioral/severity dimension; affective dimension; sensory dimension; and cognitive / mood dimension.

1. Perception in behavioral/severity dimension means that individual perceives fatigue from movement ability or doing daily activities such as working, studying, and engagement in social activities. Piper believes that fatigue mechanism is of reaction within the body that effects movement ability.

2. Perception in affective dimension means individual perceives fatigue from expressing opinion or attitude towards fatigue. Piper believes that fatigue mechanism is an effect of psychological reaction on behavior.

3.Perception in sensory dimension means that individual perceives fatigue from their feeling during having fatigue, which include tiredness, exhausting, or weakness.

4. Perception in cognitive/mood dimension means that individual perceives fatigue from the ability of thought, emotion, concentration, and decision making.

Many other works regarding the study of fatigue in cancer patients illustrated that fatigue is the perception of individual in tiredness, exhaust, weakness that influence many changes within the body caused by the disease. Such tiredness brought unhappiness in different duration and severity, and effected impaired functional status of the body as well as quality of life (Kulsu, 2544: 14; Aistars, 1987: 25; Piper et al., 1987: 17-23; Richardson & Ream, 1996: 24-30).

It can be seen that perception of fatigue is personal feeling and varies among individuals. Nurses should understand about fatigue in patients' perspective and help stimulate patients to explore if such fatigue occurs and its characteristics.

#### **Evaluation of fatigue**

Evaluation of symptoms means the decision of child patients regarding the severity and duration of fatigue caused by chemotherapy, which reflects their experience of symptom from complex co-factors or their own judge about the symptom (Dodd et al., 2001: 668-676).

#### Severity of fatigue

The characteristic and severity of fatigue among child patients with cancer vary in its severity during the period of chemotherapy (Piper et al., 1987: 20), which is different among individuals. The literature review suggested that some patients reported fatigue feeling and its severity during receiving chemotherapy. The symptoms will increase according to the time of receiving chemotherapy and also change during the process (Blesch et al., 1991:81-87; Irvine et al., 1994: 367-378; Winningham et al., 1994: 23-36).

At present, various instruments have been developed to evaluate the severity of fatigue in cancer patients, for, example, Fatigue Scales developed by Oncology Nursing Society, interview questionnaire with yes /no question, or checklist, etc. In this study, the researcher applied Fatigue Scales of Oncology Nursing Society to evaluate the severity of fatigue among child patients. The instrument is visual analogue scales type of 10 levels, starting from 0-10 scores, with straight line and defined numbers or pictures to identify the level of fatigue (Oncology Nursing Society, 2000). The instrument was modified for more conveniently use, that is, the numeric rating scale of 10 levels, in which the level of severity was identified as in the concept of evaluation of Oncology Nursing Society.

#### **Duration of fatigue**

Regarding the time when fatigue occurs during the day among child patients with cancer, Langeveld et al. (2000, cited in Kulsu, 2544: 27) had conducted interviews about experience of weakness among 35 patients surviving from leukemia, cancer at lymphatic glands, brain cancer, and severe malignancy during their childhood, and found that each patient experienced different duration of fatigue during the day but mostly during the morning or after bed although having full sleeping for more than 9 hours. Only some reported having fatigue during the afternoon or evening. Once the fatigue occurred, it remained for almost all the time. Similarly, the study of Kulsu (2544: 53) showed that the time the child patients reported having most fatigue during chemotherapy treatment is after bed, followed by the evening time. Moreover, studies among adult patients revealed that fatigue was mostly occurred during the afternoon and evening time (Saejew, 2001: 62; Greenberge et.al., 1992: 38-45).

#### **Causes of fatigue**

Causes of fatigue in child patients are not well known. According to the concept of Piper et al. (1987: 17-23) in his Integrated Fatigue Model, she described that fatigue in cancer patients have many causes comprising 13 patterns, caused by multi-causes which include physiological, psychological, emotional, and social causes. Once fatigue occurred, individual perceived it differently in 4 dimensions: behavioral / severity dimension; affective dimension; sensory dimension; and cognitive / mood dimension.

Aistars (1987: 25) stated that fatigue has many causes. He applied the theory of energy and stress to explain that fatigue caused by both physical and psychological factors including the situation that effect stress and loss of energy, which might come from the disease, treatment, activities, and insufficient rest. These factors make the body become stress and express as physical and psychological fatigue.

Richardson & Ream (1996: 24-30) studied about fatigue experience and other symptoms found in 129 cancer patients receiving chemotherapy especially regarding the perception of fatigue of cancer patients, and causes of fatigue during receiving chemotherapy. The researcher applied the instruments in 2 methods, 1). Record of fatigue - the patients record their fatigue everyday during chemotherapy period, presented in visual analogue scales, and 2) interviews. The findings showed that 85 % (110 cases) had experienced fatigue, while one case cannot identify the cause of fatigue. The patients who perceived causes of fatigue were classified as follows: 47% caused by treatment, i.e. chemotherapy, medicines, or other treatment, and radiotherapy; 16% caused by the pattern of activities and rest, i.e. doing a lot of activities, waiting/visiting hospital; 14 % caused by other pattern, i.e. various symptoms, receiving insufficient food, and environment; 9 % was related to factors like advanced age etc.; 9% from the cancer in combination with complications; 9 % was sleeping/getting up pattern, i.e. insufficient sleeping/change of sleeping pattern; 2% from psychological factor like anxiety and boring; and 3% was uncertain or no response.

#### **Response to fatigue**

According to the review of literature, fatigue varies in duration and severity among individuals and was responded differently as follows:

1. Physically response occurs when the body uses increased energy especially stored energy that hence causes exhausting, weakness, delayed movement and lethargic (Aistars, 1987: 25-30; Hart et al., 1990: 967-976; Larson et al., 1993: 473-480; Piper, 1991: 894-905; 1993: 279-302). Richardson & Ream (1996: 24-30) conducted a study on fatigue experience and other symptoms among 129 cases of cancer patients receiving chemotherapy and reported the expressed symptoms of fatigue during chemotherapy treatment that 63% of cases experienced changes of feeling such as breathing trouble, pain, change of smell and taste. About 18% had changes in control such as giddy, loss of appetite, increased body temperature, shaking, etc. There were 13% reported insomnia, alopecia, neutropenia, high fever and chilly, and stress, whereas 5% had changes in movement such as stress/weak muscles.

2. Psychological and emotional response to fatigue was expressed as easily loss of temper (Piper et al., 1987: 17-23) inconsistent emotion, become inferior and inability, unsuccessful, and loss of self control ability. Children at this age cannot bear to feeling of reduced control power and loss of self-respect, become inferior and fear of being refused by peers, and hence become emotional stress, lonely, lethargic and depress (Hart et al., 1990: 967-976; Piper et al., 1987: 17-23).

3. Behavioral response to fatigue was presented as disengagement to work or activities, failure to success, and no social activities or no interrelation with others and social isolation. Finally, children may have impaired movement ability, tiredness, weakness, inability to move legs and arms or even to open eyes, and thus need more sleeping. They become unable to perform normal activities, to engage in social activities, and to perform desired activities like playing and joining activities with friends such as sports or school activities (Aistars, 1987: 25-30; Hinds et al., 1999a: 277-289; 1999b: 37-45; Hockenberry-Eaton et al., 1998: 172-182)

It can be seen that patients with different fatigue experiences have different physical and emotional responses to it according to the evaluation of the level of severity and life threatening of such fatigue. The review of literature found very less studies and reports about fatigue experience especially among child patients, so did the report on instruments used for measuring fatigue experience.

#### Fatigue outcomes interference with functional status

The severity of fatigue effects physiologically and psychosocially on child patients with leukemia. Physiologically, fatigue caused reduced movement ability. Normally, movement development among school children aged 7-12 years is an increased skill in using muscles in coordinating with nervous system since the muscle had far developed and become stronger to support active movement such as running and playing, jumping and climbing with well-balance of body, performing activities of daily living, self dressing, bathing and shampooing, and better brushing teeth (Taiyapirom, 2541: 123). Fatigue reduced normal movement ability in children and makes them feel tired and exhaust, weak, unable to move arms and legs even open eyes, hence requiring more sleep and rest. Children cannot practice their normal activities, participate in social functions, perform desired activities (Hinds et al., 1999a: 277-289; 1999b: 37-45; Hockenberry-Eaton et al., 1998: 172-182; Mock & Olsen, 2003: 36)

#### **Fatigue management strategies**

Fatigue is commonly found among child patients with cancer receiving chemotherapy treatment with least cured and low level of success, and hence affects reduced functional status of body and quality of life. Therefore, once having fatigue, children have to find effective strategies to manage it. Review of literature had suggested many strategies of fatigue management.

Nail & Winningham (1993: 608-619) cited that assistance to reduce fatigue in patients with cancer is to give advise and knowledge about fatigue, how to store energy, how to manage activities, enough rest, and exercise.

Hinds et al. (1999a: 281-286) explained that to reduce fatigue, one should understand what influences fatigue among child patients who had cancer and try to eliminate factors that cause fatigue. They had studied patients' perspective regarding fatigue among 4 groups including those aged between 7-12 years, 13-18 years, parents and personnel attending care for child patients having cancer. In this study the researcher aimed to examine the child patients aged 7-12 years, and the finding revealed that the need to reduce fatigue as perceived by child patients includes taking naps, having visitors, and doing fun activities.

Pritsanapanurungsie (2001; 97) studied about self-care action and effectiveness of self-care action to mange fatigue in 30 breast-cancer patients receiving chemotherapy. The results showed that self-care action to manage fatigue was lying down which effect almost complete relief. Others self-care actions were praying, meditation, working, traveling, and listening to dhamma tape.

Saejew (2001: 67-68) conducted a study among 60 head and neck cancer patients and reported that most frequency used self-care actions to manage fatigue were lying down and sleeping, while stopping radiation therapy was the most effective strategy.

Mock & Olsen (2003: 38-39) explained to the management of fatigue include both nonpharmacologic and pharmacologic therapies. Nonpharmacologic therapy such as energy conservation, distraction and stress management etc. This paper suggested excercise offers the strongest evidence of value in alleviating cancer-related fatigue. Pharmacologic therapy for fatigue should be based on any specific causes identified during the patient's assessment explained.

According to the review of related literature, the strategies to help prevent and reduce fatigue among child patients with cancer are rest and taking nap, exercise, meditation, eating, having visitors, doing fun activities or hobby such as listening to music, watching T.V. and reading books, etc.

Fatigue is the perception of individual's feeling of tiredness and exhausting, which are influenced by changes within the body. Fatigue is commonly found in child patients with cancer who receive chemotherapy. Such feeling causes unhappiness with different level of severity and duration. Individual can perceive fatigue as personal feeling observed by physical and psychological expression that affects impairment of body function and reduced quality of life. Once experiencing fatigue, the patients will interpret fatigue according to their perspective and its severity. Patients will observe factors affecting increased or reduced fatigue, and then develop strategies to manage such fatigue in order to prevent, reduce it with various means

during having acute symptom, and make adjustment for a long period so that they can continue normal life. Related research provided knowledge and understanding about fatigue. However, such feeling is commonly occurred and unavoidable among those child patients with cancer who undergo chemotherapy treatment. Related research on fatigue were rarely found in Thailand, and no report was found about fatigue experience, its effect, and how to manage it especially among 7 - 12 year-old-child patients who had cancer and received chemotherapy. Fatigue is a complex phenomenon and differs among individuals, and that requires different management. Studies about fatigue experience provide clear understanding about perception of fatigue, its severity, duration, causes, response, and effects, including strategies to manage it by child patients. Moreover, patients can observe their own fatigue experience and effect, and learn about the disease, as well as sharing to manage it (Larson et al., 1994: 273). The patients will realize the importance of reviewing their past experience about causes of such abnormality and strategies they managed it, then apply and improve it for further and effective management that leads to better quality of life.

#### CHAPTER 3

#### **MATERIALS AND METHODS**

This descriptive research aimed to explore the fatigue experience, fatigue outcomes interference with functional status, and fatigue management strategies in leukemic children receiving chemotherapy.

#### **Population and sample**

The population in this study is leukemic children receiving chemotherapy at the in-patient department of Ramathibodi Hospital, King Chulalongkorn Memorial Hospital, and Queen Sirikit National Institute of Child Health. Purposive sampling was undertaken to select samples who meet the following criteria:

- 1. Being on the  $3^{rd}$  day of chemotherapy process.
- 2. Having fatigue within 24 hours prior to the study.
- 3. Being able to understand and speak Thai.
- 4. Being well oriented at the beginning of the study.
- 5. Providing consent to participate in this study from caregiver.

The exclusion criteria for those unqualified in this study are:

- Receiving radiation therapy, bone marrow transplantation and operation during the study.
- 2. Have life-threatening condition and on endotrachial intubation.

Sample size was derived from estimation of population proportion. In this study, the actual number of population was unknown since the study was conducted in different areas. Therefore, in this case, calculation for the population size with unknown p or q value was done by defining p at 0.5, the highest value, when q = 1- p. Hence, q = 0.5 and pq = 0.25 or 1/4 (Vanichbuncha, B.E. 2545: 74)accepting maximum 10 % of error, with confidential level at 0.05. Then calculation was made to find the sample size, employing the following formula:

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n = 
$$Z^{2}_{1-\alpha/2}pq$$
 =  $Z^{2}_{1-\alpha/2}$   
E<sup>2</sup> 4E<sup>2</sup>

$$= \frac{(1.960)^2}{4(0.10)^2} = 96.04$$

Where:

1-α	=	Confidential level
Ζ	=	Z value from Z Table
р	=	proportion of interested population
q	=	proportion of uninterested population, $q = 1 - p$
Е	=	error accepted in estimation

The data was collected in seven-month-period from March to September, 2003. Total 55 cases, 50 cases of leukemic children were selected and 5 cases had not fatigue, because which studied had less leukemic children admitted to receiving chemotherapy.

#### Setting

Place of data collecting in this study comprised of pediatric ward II of Ramathibodi Hospital, Hemato-oncology pediatric ward of King Chulalongkorn Memorial Hospital, and Institute 8 pediatric ward of Queen Sirikit National Institute of Child Health which have the following characteristics.

1. Pediatric ward II of Ramathibodi Hospital is a general in-patients ward which has 28 beds for child patients age 5 - 15 years with general illness except infectious disease. The visiting time permitted is on 8.00 a.m.- 8.00 p.m. In case of management for cancer child patients, there were 2 oncologist doctors and registered nurses for taking care of patients. Management way concerning chemotherapy receiving were advised for child patients and parents of child patients were also got handbook of management procedure for chemotherapy-receiving patients. Additionally, there is a recreational room in this ward which is available for patients and parents in office-hour. There are 2 officers in the recreational room who conduct the recreational activities for patients such as watching TV, playing games and stories telling. Whereas, there is a book corner and three TV corners for patients during non-office-hour.

2. Hemato-oncology pediatric ward of King Chulalongkorn Memorial Hospital is served for children from neonate to 15 years of age who have blood disorder or renal disease. There are 26 beds in this ward and visiting time permitted is on 9.00a.m. – 8.00 p.m. In case of management for cancer child patients, there were 3 oncologist doctors and registered nurses for taking care of patients. Management way concerning chemotherapy receiving were advised for child patients and parents of child patients were also got handbook of management procedure for chemotherapy-receiving patients. Furthermore, there is a recreational room in this ward, which has books, toys, and televisions available for patients in the afternoon. In additions, there are volunteer of Christians conduct the recreational activities for patients every Friday on 2.00 p.m. – 4.00 p.m. In case of independent children, they are permitted to go out with nurse aids to use computers at  $12^{th}$  floor.

3. Institute 8 pediatric ward Queen Sirikit National Institute of Child Health is 32-bed ward served for children age between 1 month and 18 years who have blood disorder, brain disorder, heart disease, and renal disease except infectious disease. Additionally, there are separate rooms for low-immune patients. The visiting time permitted is on 9.00 a.m. – 9.00 p.m. and one female caregiver is permitted for each patients. This ward is served for children with all kinds of cancer and there were 3 oncologist doctors and registered nurses for taking care of patients. Management way concerning chemotherapy receiving were advised for child patients and parents of child patients were also got handbook of management procedure for chemotherapyreceiving patients. Furthermore, there is a recreational room in this ward, which has books, toys, and televisions available for patients. Additionally, there is computer center for patients to learn during being admitted in the hospital.

#### Instruments

Demographic Characteristics and Clinical Data Form (See Appendix
B) Developing by the researcher. The form consisted of 3 parts as follows:
**Part 1 Individual information of the child patients** will include age, sex and educational level. The data deriving from interviews.

**Part 2 The disease and treatment information** will include diagnosis of disease, duration of illness, duration of receiving chemotherapy, numbers of hospital admission, number of receiving chemotherapy, type of chemotherapy, side effects of chemotherapy, and hemoglobin level. The data derived from the client's record.

**Part 3 Information on general symptom of the child patients** will include general characteristics of the child patients, speech characteristic, movement characteristic, and ability to perform activities. The data derived from observation of patients' behavior during the interviews.

**2. Fatigue interview form** (See Appendix C) This form was developed by the researcher by adopting the revised fatigue management concept of Dodd et al. (2001), and reviewing of related literature. Fatigue interview form compiled description of feeling of the patients towards fatigue experience, its effects on functional status, as perceived by the samples. The form included 11 items, divided into 4 parts as follows:

**Part 1 Perception of fatigue** This part compile information on the evaluation of fatigue caused by chemotherapy. This part consisted of 1 item of openended question, allowing patients to describe the nature of fatigue experience.

**Part 2 Evaluation of fatigue** The child patients make self judge regarding the severity, duration and causes of fatigue caused by chemotherapy. This part consisted 3 items:

1. Evaluation of the severity of fatigue, applying Numeric Rating Scale of 10 levels from 0-10. The level of severity of fatigue was defined according to the concept of fatigue evaluation form (Oncology Nursing Society, 2000), that is,

- 0 = No fatigue
- 1-3 = Mild fatigue
- 4-6 = Moderate fatigue
- 7-9 = Extreme fatigue
- 10 = The worst fatigue

2. Duration of fatigue consisted 1 item of close-ended question type with multiple choices of time each fatigue occurred.

3. Causes of fatigue consisted 1 item of close-ended question type with multiple choices of causes of fatigue as perceived by the patients, more than one answers as well as additional answers are accepted.

**Part 3 Response to fatigue** This part included physical, mental, and behavioral response of the child patients towards fatigue, consisting 3 items of closeended question type with multiple choices of actual behaviors after feeling fatigue. More than 1 choice and additional answers are accepted.

**Part 4 Fatigue outcomes interference with functional status** The effects of Fatigue experience interfering functional status include performing activities of daily living, walking and physical movement, playing and doing desired activities. The form was developed by the researcher modifying from the Revised Piper Fatigue Scale (Piper et al., 1998). The form comprised 4 items applying Numeric Rating Scale with the 10 levels of rating scale from 0-10. The level of interference is divided into level according to the concept of Fatigue evaluation form (Oncology Nursing Society, 2000).

0 = No interference
1-3 = Mild interference
4-6 = Moderate interference
7-9 = Extreme interference
10 = The worst interference

**3.** Interview form on fatigue management of leukemic child patients receiving chemotherapy (See Appendix D). The form was constructed by the researcher by applying the concept of Revised fatigue Management developed by Dodd et al. (2001), and reviewing of literature. The form consisted of 15 items with 2 answering choices, i.e. NO and YES. In case the samples selected certain activity to manage fatigue, they are to identify the effectiveness of such strategy in fatigue management, based on self-judged of the child patients. The level of measurement presented by interval from 0-2 scores. Additional answers are accepted.

- 0 = Not relieved1 = Moderate relieved
- 2 = Completely relieved

### Quality testing of the instrument

### Validity of questionnaire

This interview form was evaluated for content validity, language suitability, and scoring criteria by 1 nurse who had experience in nursing patient cancer, and 4 nursing educators who are experts in the model of symptom management and care for cancer patients (see Appendix E). The interview form was then modified based on the experts' comments and suggestions.

### Reliability

Fatigue interview form in Part 4: the fatigue outcomes interference with functional status was tested for reliability by using Cronbach's Alpha among 20 school age children with leukemia who had similar characteristics to the samples in this study. The reliability is 0.8766. When this tool was used with 50 subjects. The reliability is 0.8239.

### **Protection of Human Subjects**

The human rights were seriously taken into respect in this study (See Appendix A). Eligible samples were asked in the study. The researcher had explained the purpose of the study, research procedure, benefits, type of interview form, length of time for completing the interview form, and the right to refuse to caregiver and participate in the study. The samples' caregiver that consent to participate in the study were informed and assured that the data will be kept strictly confidential and will be reported only in group data.

### **Data Collection**

After permission was secured from the Faculty of Graduate Studies, Mahidol University, data collection were proceeded as follows:

1. Approaching the Human Subject Committee (HSC) and asking for permission and facilitation in collecting data by submitting official document from the Faculty of Graduate Studies, Mahidol University to Faculty of medicine, the Heads of Ramathibodi Hospital; King Chulalongkorn Memorial Hospital; and Queen Sirikit National Institute of Child Health. The researcher was permitted to collect data between 9:00 - 11.00 a.m. and 1.00 - 3.00 p.m. during non professional giving treatment or procedure and don't have grouptherapy such as watching TV, playing games and telling stories. Duration of collecting data between March to September, 2003, according to the following schedule:

Wednesday: Hemato-oncology pediatric ward of King Chulalongkorn Memorial Hospital

Thursday: Institute 8 pediatric ward Queen Sirikit National Institute of Child Health

Friday: Pediatric ward II of Ramathibodi Hospital

Sunday: Institute 8 pediatric ward Queen Sirikit National Institute of Child Health

2. The researcher make relationship by introduce, talking with he/she and parent/caregiver about symptoms and treatment, then identified the patients who meet the eligibility criteria by reviewing medical records and purposively selecting the samples.

3. The researcher prepared a place for collecting data, facilitated by the caregivers.

4. To protect the rights of individual sample, each of the patient and the caregiver is asked to sign in a consent form which includes an explanation about the purpose of the study, assurance of confidentiality and anonymity, and the freedom to withdraw from the study at anytime.

5. After the patients and caregivers agreed to participate in this study, the researcher explained the method of answering the interview form.

5.1 Demographic Characteristics and Clinical Data Form. This interview form consisted of 3 parts. The first part is demographic characteristic, collected by asking the patients and the caregivers. The second part is clinical data, derived from medical records. The third part is behaviors and characteristics of the patients, collected by observing the patients during interviews.

5.2 Interview form of fatigue and interview form of fatigue management strategies in leukemic children receiving chemotherapy were collected by asking the patients only.

5.3 The researcher interviewed the samples and made record in the interview form. After completing data collection, the researcher checked whether all items in the interview form are completed. It took about 20-30 minutes for each case. The researcher had collected the data no more 4 cases per day, and the data was not recollected from the same sample.

### Data analysis

1. The Demographic Characteristics and Clinical Data were analyzed in frequency, percentage, mean, median and standard deviation.

2. The fatigue experience include perception, evaluation and response to fatigue

2.1 Fatigue perception was assessed by interviewing with one open – ended question then the data were categorized by the researcher and analyzed in percentage and frequency.

2.2 Evaluation and response to fatigue was analyzed in frequency, percentage, mean, median and standard deviation.

2.3 The fatigue outcome interference with functional status was analyzed in frequency, percentage, mean, and standard deviation.

3. The fatigue management strategies and the effectiveness of fatigue management strategies were analyzed in frequency, percentage and mean.

### CHAPTER 4 RESULTS

This descriptive research studied the fatigue experience, fatigue outcomes interference with functional status and fatigue management strategies in leukemic children receiving chemotherapy. The results which composed of characteristics of samples, fatigue experience, fatigue outcomes interference with functional status and fatigue management strategies were presented in the tables, respectively.

### Part 1 Characteristic of samples

Participants were recruited from acute leukemic children who admitted in Pediatric ward II at Ramathibodi Hospital 23 samples. Moreover, samples were selected from Institute 8 pediatric ward at Queen Sirikit National Institute of Children Health 24 samples and from Hemato-oncology pediatric ward of King Chulalongkorn Memorial Hospital 3 samples. Samples were totally 50 participants which age ranged 7-12 years, mean and median age were 9.86 and 10 years. Additionally, Sixty-two percents of samples were male and studied in primary school level 4-6 as shown in Table 1.

Table 1.	Frequency and	percentage of	characteristic	of the	samples	(n=50)
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racteristics		Frequency	Percentage
7-9 years		24	48
10-12 years		26	52
(Mean =9.86	5, S.D. = 1.81)		
Male		31	62
Female		19	38
tional Level	Prathom 1-3 (Grade 1-3)	) 19	38
	Prathom 4-6 (Grade 4-6)	) 31	62
	racteristics 7-9 years 10-12 years (Mean =9.86 Male Female tional Level	racteristics7-9 years10-12 years(Mean =9.86, S.D. = 1.81)MaleFemaletional LevelPrathom 1-3 (Grade 1-3 Prathom 4-6 (Grade 4-6)	racteristics       Frequency         7-9 years       24         10-12 years       26         (Mean =9.86, S.D. = 1.81)       31         Male       31         Female       19         tional Level       Prathom 1-3 (Grade 1-3)       19         Prathom 4-6 (Grade 4-6)       31

#### **Disease and treatment of the samples**

Most of samples (70%) were acute lymphoblastic leukemic children (ALL) who require induction treatment 46%. The rest of samples were non-lymphoblastic leukemia children (ANLL) who require induction treatment 24%. In case of illness duration, 70 percents of samples were ill for 1 to 12 months. Samples who have number of admission less than 10 times were 48 percents. Fifty percents was treated with chemotherapy less than 10 times and 50% was treated more than 5 times. Types of chemotherapy were Antimetabolites (66%) such as high dose methotrexate, Cytosine arabinoside (Ara-C), 58 percents were Plant Alkaloid such as Vincristine, Etoposide, Hormones, and 54 percents were Hormones that's Prednisolone. Eighty-eight percents of samples have side effects of chemotherapy. The side effects that found were nausea and vomiting (52%) fever (39%) and bleeding (30%). Hemoglobin level was found in moderate level (8-9.9 g/dl), which were 46 percents of samples as shown in Table 2.

Data	Frequency	Percentage
Diagnosis		
ALL	35	70
ANLL	15	30
Duration of illness		
1-12 month	35	70
13-24 month	11	22
25-36 month	4	8
Treatment of leukemia		
ALL: Induction	23	46
Consolidation	2	4
CNS prophylaxis	10	20
ANLL: Induction	12	24
Intensification	1	2
Maintenance	2	4

Table 2 Frequency and percentage of disease and treatment of samples (n = 50)

### Table 2. (Continued)

Data	Frequency	Percentage
A number of admissions		
1-5 times	24	48
6-10 times	11	22
>10 times	15	30
A number of receiving chemotherapy		
1-10 times	25	50
11-20times	25	50
Type of chemotherapy		
Antimetabolites	33	66
Plant Alkaloid	29	58
Hormones	27	54
Alkalating Agents	10	20
Antitumor antibiotics	7	14
Miscellaneous agent	5	10
Side effects of chemotherapy		
No side effects of chemotherapy	6	12
Side effects of chemotherapy	44	88
Nausea and vomiting	23	52
Fever	17	39
Bleeding	13	30
Mucositis	8	18
Diarrhea	4	9
Hemoglobin level		
Mild anemia (10-11 g/dl)	15	30
Moderate anemia (8-9.9 g/dl)	23	46
Severe anemia (6.5-7.9 g/dl)	12	24

### **Clinical data of samples**

Acute leukemic children during interview were in supine position (66%). Fiftytwo percents had cheerless face, 82 percents were pale in lower eye lid and lip, 80 percents of samples spoke quietly, 66 percents had slow movement, and 82 percents were independence in doing any activities as shown in Table 3.

Clinical data	Frequency	Percentage	
General appearance			
Position			
Supine	33	66	
Sitting	17	34	
Face			
Cheerless	26	52	
Cheerful	24	48	
Lip			
Not pale	6	12	
Mild pale	41	82	
Severe pale	3	6	
Eye lid			
Not pale	6	12	
Mild pale	41	82	
Severe pale	3	6	
Speech			
Quiet	40	80	
Clear and Fluent	10	20	
Movement			
Slow	33	66	
Fluent	17	34	
Doing activities			
Independent	41	82	
Dependent	9	18	

Table 3 Frequency and percentage of clinical data of the samples (n = 50)

Research question 1 What were the nature and extent of fatigue experience among leukemic children receiving chemotherapy?

#### **Fatigue Experience**

### 1. Fatigue perception

### Characteristics of fatigue perception of samples (n = 50)

Fatigue perception was assessed by interviewing with open question then the data can be categorized into 3 themes. theme 1(72%): Physical changes such as headache, dizziness, etc, theme 2 (64%): Feeling tired and weak, and theme 3 (20%): Being unable to do usual activities. From interviewing, there are 2 patients who did not answer the question as shown in Table 4.

Fatigue perception*	Frequency	Percentage
1. Physical changes:	36	72
(headache, dizziness, etc.)		
2. Feeling tired and weak	32	64
3. Being unable to do usual activities	10	20

### Table 4 Frequency and percentage of fatigue perception of samples (n = 50)

\* 1 sample may answer more than one item.

### 2. Assessment of fatigue

### 2.1. Fatigue level of sample

Sixty-eight percents of samples were in moderate level of fatigue during assessment. Mean and median of fatigue level were 5.52 and 5.00 as shown in Table 5.

# Table 5. Frequency, percentage, mean and standard deviation of severity of fatigue perceived by the samples experiencing fatigue during chemotherapy (n = 50)

Fatigue intensity	Frequency	Percentage	
Mild fatigue	5	10	
Moderate fatigue	34	68	
Extreme fatigue	8	16	
The worst fatigue	3	6	
(Mean = 5.52, S.D.= 2.07)			

### 2.2. Duration of fatigue

Sixty-two percents of samples had much fatigue in the afternoon as shown in Table 6.

# Table 6. Frequency and percentage of duration of fatigue perceived by thesamples experiencing fatigue during chemotherapy (n = 50)

Duration of fatigue	Frequency	Percentage
Morning	8	16
Afternoon	31	62
Evening	5	10
Night	6	12

### 2.3 Causes of fatigue

Fatigue of acute leukemic children caused mostly by receiving chemotherapy which was 80 percents of samples. Seventy-six percents of samples were acute leukemia disease and nausea and vomiting (52 %). Additionally, the causes of fatigue that children described were much playing, walking, running while the mild fatigue occurred during chatting with siblings, not playing and having ulcers in mouth as shown in Table 7.

	Causes of fatigue*	Frequency	Percentage
1.	Receiving chemotherapy	40	80
2.	Disease	38	76
3.	Nausea and vomiting	26	52
4.	Inadequate sleep	25	50
5.	Fever	24	48
6.	Less food intake	19	38
7.	Admit hospital	17	34
8.	Sleep interruptions	14	28
9.	Hospital sound interruption	14	28
10.	Receiving painful procedure	13	26
11.	Diarrhea	5	10
12.	Decreased Relatives siblings and friends	4	8
13.	Mucositis	4	8
14.	Others	1	2

# Table 7. Frequency and percentage of causes of fatigue perceived by the samplesduring chemotherapy (n = 50)

\* 1 sample may define causes of fatigue more than 1 symptom.

### 3. Response to fatigue

### 3.1. Physical response to fatigue

The most physical response to fatigue that acute leukemic children reported were muscle fatigue and pain which was 86 percents. Fifty percents of samples had headache and muscle of limbs weakness. Additionally, the symptoms that acute leukemic children perceived were fasciculation of hand, dizziness, exhausted and hyperpnea as shown in Table 8.

the samples during enemotier	apy (n 50)	
Physical response * Frequency Percenta		
1. Muscle fatigue and pain	43	86
2. Headache	25	50
3. Weakness of limbs	25	50
4. Numbness of fingers and toes	21	42
5. Confusion	18	36
6. Fasciculation of limbs	13	26
7. Fasciculation of eyelid	7	14
8. Eye pain	3	6
9. Others	3	6

### Table 8. Frequency and percentage of physical response to fatigue perceived by the samples during chemotherapy (n = 50)

\* 1 sample may report more than one symptom.

### 3.2. Psychological and emotional response to fatigue

Seventy percents of acute leukemic children in this study reported that the psychological and emotional response to fatigue was Anxiety and fear of their own future. Furthermore, sixty-two percents described the psychological and emotional response as easily irritable and thirty percents had response of depression and not concentrated mind as shown in Table 9.

Table 9. Frequency and percentage of psychological and emotional response to fatigue perceived by the samples experiencing fatigue during chemotherapy (n = 50)

Р	sychological and emotional response*	Frequency	Percentage
1.	Anxiety and fear of own future ie,	35	70
	fear of pain when receiving chemotherapy		
2.	Easily irritable	31	62
3.	Depress	15	30
4.	Not concentrated mind	15	30
5.	No self confidence ie, not believe that they		
	can go to the toilet independently	14	28
6.	Serious	4	8

\* 1 sample may report more than one symptom.

### 3.3 Behavioral response to fatigue

The behavioral response that samples reported mostly was Drowsiness i.e., low spirits which was 74 percents. Sixty-two percents of samples described the response as always sleepy and not active. In addition, there were 60 % that would like to lie down as shown in Table 10.

	Behavioral response*	Frequency	Percentage
1.	Drowsiness i.e., low spirits	37	74
2.	Always sleepy	31	62
3.	Not active	31	62
4.	Would like to lie down	30	60
5.	Decrease in to do activities of daily living	27	54
	i.e., unable to go to the toilet dependetly,		
	unable to eat dependently		
6.	Not stable standing	19	38
7.	Exhausted during talking	13	26
8.	Unable to erect posture ie, upright standing	12	24
	or sitting		

# Table 10 Frequency and percentage of behavioral response to fatigue perceivedby the samples experiencing fatigue during chemotherapy (n = 50)

\* 1 sample may have more than one behavioral response.

# Research question 2 How did the fatigue outcomes interfere functional status of those leukemic children receiving chemotherapy?

### Fatigue outcomes interfere with functional status

Acute leukemic children reported that their fatigue perception can interfere the functional status at moderate level. In the other words, the fatigue disturbed doing activities of daily living, playing with their friends, walking, doing any movement, and fun activities such as playing sport as shown in Table 11.

Fatigue outcomes	Frequency	Percentage				
Activity of daily living						
No interference	2	4				
Mild interference	15	30				
Moderate interference	21	42				
Extreme interference	10	20				
The worst interference	2	4				
(Mean = 4.60, S.D. = 2.44)						
Talking and/or playing with other children						
No interference	5	10				
Mild interference	11	22				
Moderate interference	22	44				
Extreme interference	12	24				
(Mean = 4.54, S.D= 2.25)						
Walking and movement						
No interference	1	2				
Mild interference	10	20				
Moderate interference	20	40				
Extreme interference	19	38				
(Mean = 5.34, S.D. = 2.69)						
Playing or perform preferring activities						
No interference	3	6				
Mild interference	12	24				
Moderate interference	21	42				
Extreme interference	12	24				
The worst interference	2	4				
(Mean = 5.02, S.D. = 2.58)						

## Research question 3 What were the fatigue management strategies for leukemic children receiving chemotherapy?

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Research question 4 How did the effectiveness of fatigue management strategies perceived by leukemic children receiving chemotherapy?
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### **Fatigue management strategies**

The management strategy, which most samples chosen, to do against the fatigue was sleeping (100%). Other strategy was talking with friends, siblings or parents, which were 98 percents. Additionally, there were 88 percents reported their fatigue management strategy as eating nutritional food. In case of effectiveness of management strategies, the most effective strategy was sleeping. Meditating, listening to music, and medication were also used to manage with fatigue. Furthermore, the other management strategies were sitting and drinking juice as shown in Table 12.

Table 12. Frequency, percentage and mean of fatigue management strategies andeffective of fatigue management strategiesperceived by the samples

Fa	tigue management strategies*	Frequency	Percentage	Effective Mean
1)	Sleeping	50	100	1.70
2)	Talking with friends, siblings or paren	nts 49	98	1.24
3)	Eating nutritional food	44	88	1.36
4)	Taking naps	41	82	1.07
5)	Stopping what one is doing	41	82	1.24
6)	Watching television	39	78	1.33
7)	Medication	30	60	1.50
8)	Reading favorite book	30	60	1.27
9)	Playing	29	58	1.21
10)	Walking	26	52	1.00
11)	Listening to music	20	40	1.50
12)	Attending recreational activities	19	38	1.47
13)	Attending sermons of the monks	10	20	1.00
14)	Meditating	3	6	1.67
15)	Others	2	4	1.50

experiencing fatigue during chemotherapy (n = 50)

\* 1 sample may use more than one strategy.

### CHAPTER 5 DISCUSSION

This study was the descriptive research and was aimed to study fatigue experience, fatigue outcomes and fatigue management strategies in leukemic patients aged 7-12 years receiving chemotherapy. The discussion was explained in the following sections; fatigue experience, fatigue outcomes interference with functional status and fatigue management strategies of leukemic children

### Research question 1 What were the nature and extent of fatigue experience among leukemic children receiving chemotherapy?

### **Fatigue experience**

Fatigue experience was composed of perception of fatigue, assessment of fatigue, and response to fatigue.

### 1. Perception of fatigue

Perception of fatigue was categorized into 3 themes; theme 1: Physical changes, theme 2: Feeling tired and weak, and theme 3: Being unable to do usual activities. There were two patients who did not answer the question. This might be due to low level of relationship between the researcher and children since a period of making relationship with the children was very short. Additionally, two children who did not answer the question of fatigue regarding experiencing physical changes, feeling tired and weak, and being unable to do usual activities were 72%, 64%, and 20%, respectively (Table 4). As the results shown, perception of fatigue was an individual perception which have variability. In additions, the results of the present study supported other research regarding the perception of fatigue of leukemic patients, which found that perception of fatigue was the feeling of exhaustion and weakness

which caused discomfort, impairment of body function and reduced quality of life (Kulsu, 2544: 14; Aistars, 1987: 25; Piper et al., 1987: 17-23; Richardson & Ream, 1996: 24-30).

### 2. Assessment of fatigue

### 2.1. Severity of fatigue

Sixty-eight percents of sample were in moderate level of fatigue. Mean and median of fatigue level were 5.52 and 5.00 (Table 5). The level of fatigue was not investigated by other researchers because of fatigue severity may change during chemotherapy and varies of individuals (Pritsanapanurungsie, 2000: 58; Berger, 1998: 54; Piper, 1991: 348). The moderate fatigue level of children may be durig to 46 percents of sample had moderate level of hemoglobin (8-9.9 g/dl) (Table 2). Furthermore, eighty-two percents of the sample were mild pale in lower eyelids and lips and independent in doing activities (Table 3). Additionally, the interview was done in daytime when parents and relatives of children were bedside them and help the children feel warm, relax and were not anxiety and fear of interview. In case of fatigue management strategies, talking with friends, siblings or parents was most chosen to manage fatigue (98%) and the mean of efficacy of this strategy was 1.24 (Table 12). Additionally, there were plenty of sections available for children to play in these three hospitals of this study. Furthermore, there were group activities for children leaded by health team from both government and private hospitals. As mention above, these may affect moderate level of fatigue in children.

#### **2.2.Duration of fatigue**

Sixty-two percents of the sample reported the highest feeling of fatigue in the afternoon (Table 6). This finding is contrast to the study of Langeveal et al. (2000, cited in Kulsu, 2544: 27) who had conducted interviews about experience of weakness among 35 patients surviving from leukemia, cancer at lymphatic glands, brain cancer, and severe malignancy during their childhood, and found that each patient experienced different duration of fatigue during the day but mostly during the morning or after bed although having full sleep for more than 9 hours. Only some patients reported having fatigue during the afternoon or evening. Once the fatigue occurred, it remained for almost all the time. But the study of Kulsu (2544: 53) showed that the time the child patients reported having most fatigue during chemotherapy treatment is after bed, followed by the evening time. The result of this study supports the studies among adult patients which revealed that fatigue was mostly occurred during the afternoon and evening time (Pritsanapanurungsie, 2001:40; Saejew, 2001: 62; Greenberge et al., 1992: 38-45). Children in the present study experienced the highest level in the afternoon might be the reason that they were interviewed on the second day of receiving chemotherapy which Kulsu revealed that it was the day of peak perception of fatigue in leukemic children. Furthermore, interview was performed in office hours when children were doing their usual activities and receiving chemotherapy and the side effects of chemotherapy such as nausea and vomiting are always present. Nausea and vomiting were the most symptoms found in patients receiving chemotherapy (52%) and caused fatigue. Additionally, ward rounding and nursing care done in office hours may cause increased fatigue of children during the day.

#### 2.3. Causes of fatigue

Leukemic children reported that the most cause of fatigue was receiving chemotherapy (80%). Seventy-six percents and 52% of patients reported that fatigue was caused by the disease and nausea and vomiting. Furthermore, other causes of fatigue reported by children were much playing, walking and running (Table 7). According to the literature review, the major medication for acute lymphoblastic leukekmic children in this stage were Vincristine and Prednisolone, while the main drugs for acute non- lymphoblastic leukekmic children (ANLL) were Cytosine arabinoside (Ara-C), Vincristine, Doxorubicin and Prednisolone. Some doctors may add Etoposide (VP-16) and 6-Thioguanine (6-TG) also. Consequently, there were many drugs prescribed to use for induction stage which caused severe pancytopenia in most patients for 21-30 days (Kulpong, 2540: 83-84). Additionally, the researcher found that 82% of children had mild pale of lower eyelids and lips during interviewing and 46% of children had 8.0-9.9 g/dl of hemoglobin which was in the level of moderate anemia. Moreover, there were side effects from the therapy such as nausea, vomiting, mucositis, and diarrhea. These results correspond to various researchers which studied the factors influencing perception of fatigue in children and revealed

that fatigue was mostly caused by side effects of chemotherapy (Kulsu, 2544: 54-61, Hinds et al., 1999a: 281-286; Richardson & Ream, 1996: 24-30). In conclusion, perception of fatigue was resulted from physical changes which caused by existent of disease. In additions, there were various factors inducing perception of fatigue such as noisy, smell, light, and being awaken during sleeping, change of sleeping pattern, inability to perform desired activities, loss of appetite, side effect of chemotherapy, and suffering from pain due to treatment (Kulsu, 2544: 54-61, Hinds et al., 1999a: 281-286). In present study, all patients from three pediatric medicine units were interfered with various factors for examples, crying noise, chatting of other patients or relatives, and treating and visiting of healthcare team. Additionally, being admitted in hospital was resulted in changing of sleeping environment which caused inadequate sleeping. These reasons can be supported by the finding of present study which shown that 28% of children reported the cause of fatigue was sleep interruptions by visiting of healthcare team, 28% reported cause of hospital sound interruption such as people chatting and crying noise, 50% indicated cause of inadequate sleeping, and 38% indicated cause of less food intake.

The findings of present study were supported to Richardson & Ream (1996: 24-30) studied about fatigue experience and other symptoms found in 129 cancer patients receiving chemotherapy especially regarding the perception of fatigue of cancer patients, and causes of fatigue during receiving chemotherapy. The findings showed that 85 % (110 cases) had experienced fatigue, while one case cannot identify the cause of fatigue. The patients who perceived causes of fatigue were classified as follows: 47% caused by treatment, i.e. chemotherapy, medicines, or other treatment, and radiotherapy; 16% caused by the pattern of activities and rest, i.e. doing a lot of activities, waiting/visiting hospital; 14% caused by other pattern, i.e. various symptoms, receiving insufficient food, and environment; 9% from the cancer in combination with complications; 9% was sleeping/getting up pattern, i.e. insufficient sleeping/change of sleeping pattern; 2% from psychological factor like anxiety and boring.

#### **3.** Response to fatigue

### **3.1.** Physical response to fatigue

The most physical response to fatigue that acute leukemic children reported were muscle fatigue and pain (86%). Fifty percent of sample had headache and muscle weakness of limbs. Additionally, the symptoms that acute leukemic children perceived were fasciculation of hand, nausea, exhausted and hyperpnea (Table 8). Furthermore, the researcher had observed children during the interview and found that 66% of children had slow movement (Table 3). These findings supported various research which revealed that fatigue reduced normal movement ability in children and makes them feel tired and exhausted, weak, unable to move arms and legs even open eyes, hence requiring more sleep and rest. (Hinds et al., 1999a: 277-289; 1999b: 37-45; Hockenberry-Eaton et al., 1998: 172-182) The response of fatigue reported in the present study was similar to the study of Richardson & Ream (1996: 24-30) who conducted a study on fatigue experience and other symptoms among 129 cancer patients receiving chemotherapy and reported 63% of the experienced changes of feeling such as breathing trouble, pain, change of smell and taste. About 18% had changes in control such as giddy, loss of appetite, increased body temperature, shaking, etc. Thirteen percent of the sample reported insomnia, alopecia, neutropenia, high fever and chilly, and stress, whereas 5% had changes in movement such as stress/weak muscles.

### 3.2. Psychological and emotional response to fatigue

Seventy percent of acute leukemic children in this study reported that the psychological and emotional response to fatigue was anxiety and fear of their own future. Sixty-two percent was easily irritable and thirty percent had depression and not concentrated mind (Table 9). Additionally, the researcher had observed children during the interview and found that 52% were not cheerful which supported to many research reported that perception of fatigue can resulted in psychological and emotional response of easily loss of temper (Piper et al., 1987:17-23), inconsistent emotion, become inferior and inability, unsuccessful, and loss of self control ability. Children at this age cannot bear to feeling of reduced control power and loss of self-respect, become inferior and fear of being refused by peers, and hence become

emotional stress, lonely, lethargic, depress and frustrated (Visespanich, 2541: 2; Hart et al., 1990: 967-976; Hinds et al., 1999a: 282; Piper et al., 1987: 17-23).

#### 3.3 Behavioral response to fatigue

The behavioral response mostly reported was drowsiness and low spirits (74%). Sixty-two percent of the sample described the response as always sleepy and not active. In addition, 60 % would like to lie down, and 54% had lower in doing activities (Table 10). Furthermore, the researcher had observed children during the interview and found that children were mostly in supine position (66%), less chatting and low noise (80%), and slow movement (66%) (Table 3). These results supported various studies which reported the behavioral response to fatigue were unwanted to do any activities and unaccomplished in any works which leaded to self-isolated and then resulted in less movement. As mentioned earlier, perception of fatigue caused exhaustion, weakness, difficulty in limbs moving, and difficulty in keeping eyes open therefore children were not be able to do their usual activities, participate with friends in sports or any activities as their willingness (Aistars, 1987: 25-30; Hinds et al., 1999a: 277-289; 1999b: 37-45; Hockenberry-Eaton et al., 1998: 172-182).

## Research question 2 How did the fatigue outcomes interfere functional status of those leukemic children receiving chemotherapy?

### Fatigue outcomes interference with functional status

Acute leukemic children reported that their perception of fatigue can interfere their functional status at moderate level (Table 11). These findings supported the result of this study reguarding severity of fatigue that 68 percents of sample were in moderate level of fatigue. Furthermore, eighty-two percents of the subjects were independent in doing activities (Table 3). Additionally, the interview was done in daytime when parents and relatives of children were beside them and help the children feel warm, relax and were not anxiety and fear of interviewing. The samples were most chosen talking with friends, siblings or parents to manage with fatigue (98%) and the mean of efficacy of this strategy was 1.24 (Table 12). Additionally, there were plenty sections for children to play available in these three hospitals of this study.

Furthermore, there were group activities for children leaded by health team from both government and private hospitals. As mention above, these may affect moderate level of fatigue interfere their functional status. Moreover, supported other studies which revealed that severity of fatigue effects physiologically and psychosocially on children with leukemia. Physiologically, fatigue caused reduced movement ability. Fatigue reduced normal movement ability in children and makes them feel tired and exhausted, weak, unable to move arms and legs even open eyes, hence requiring more sleep and rest. Children cannot practice their normal activities, participate in social functions, perform desired activities such as playing and joining activities with friends or participating school activities (Hinds et al., 1999a: 277-289; 1999b: 37-45; Hockenberry-Eaton et al., 1998: 172-182; Mock & Olsen, 2003:36)

## Research question 3 What were the fatigue management strategies for leukemic children receiving chemotherapy?

Research question 4 How was the effectiveness of fatigue management strategies perceived by leukemic children receiving chemotherapy?

### **Fatigue management strategies**

The management strategy which most children chose to manage fatigue was sleeping (100%). The second strategy reported by 98% of the subjects was talking with friends, siblings or parents. Additionally, 88 percents reported their fatigue management strategy as eating nutritional food. In case of effectiveness of management strategies, the most effective strategy was sleeping. Meditating, listening to music, and taking reduce-side-effect drug of chemotherapy were also used to manage with fatigue. Furthermore, the other management strategies were sitting and drinking juice (Table 12). The results of present study corresponse to therapeutic environment and supported to the findings of Hockenberry-Eaton& Hinds (2000: 266) described protected rest time as an important factor to alleviated fatigue. Nurses felt that children benefited from uninterrupted naps and sleep time and from having plan of scheduled activities. Hinds et al. (1999a: 281-286) which explained that to reduce fatigue, one should understand what influences fatigue among children with cancer and try to eliminate factors that cause fatigue. In this study the researcher aimed to

examine the children with cancer aged 7-12 years, and the finding revealed that the need to reduce fatigue as perceived by child patients includes taking naps, having visitors, and doing fun activities. Furthermore, the results of management strategies for fatigue in this study were also likely found in the study of Pritsanapanurungsie (Pritsanapanurungsie, 2001: 104) which determined the effectiveness of fatigue management strategies in 30 cancer patients receiving chemotherapy and reported exercise and support group as management strategies. Other many management strategies for fatigue were sleeping, exercising, walking, planting, watching TV, listening to music or dhamma, reading, singing, meditating, praying, and chatting. Additionally, Sleeping was the most selected and effective management strategies reported by the subjects.

The results of present study correspond to the model of fatigue experience regarding the interaction among perception, assessment, and response to fatigue, which can affect on the body function then management strategies were chosen to deal with the symptom. According to the results, perception of fatigue found in leukemic children affects discomfort and reduced quality of life. (Hinds et al., 1999a: 282; 1999b: 37-45; Hockenberry-Eaton et al., 1998:172-182). Such perception of fatigue was a complex circumstance and had individuals' variability therefore different management strategies were chosen in each children. Consequently, the study of fatigue experience can lead to study more on the perception of fatigue, level of fatigue, causes of fatigue, duration of fatigue, response to fatigue, fatigue outcomes, and management strategies of patients.

### CHAPTER 6 CONCLUSION

This descriptive research aimed to study fatigue experience, fatigue outcomes and fatigue management strategies in leukemic children aged 7-12 years receiving chemotherapy.

### Conclusion

Participants were recruited from acute leukemic children who admitted to Ramathibodi Hospital, Queen Sirikit National Institute of Child Health, and King Chulalongkorn Memorial Hospital. Subjects were chosen between March and September, 2003 by purposive sampling. Inclusion criteria of subjects were in the third day of chemotherapy receiving, perceiving fatigue within 24 hours after participating in this, being able to communicate in Thai, having good consciousness and perception, and willingness to participate in the study. Exclusion criteria were acute leukemic children receiving the treatments such as radiotherapy, bone marrow transplantation, and operation. Coma patients who were on respirators were also excluded. Descriptive statistics was used for data analysis which can be concluded as follows;

1. Subjects were 23 acute leukemic children who were admitted to Ramathibodi Hospital, 24 subjects from Queen Sirikit National Institute of Child Health and 3 subjects from King Chulalongkorn Memorial Hospital . Subjects were totally 50 participants males more than females whose age ranged 7-12 years, mean and median age were 9.86 and 10 years. Additionally, Sixty-two percent of subjects studied in primary school level 4-6. Most samples (70%) were acute lymphoblastic leukemic children (ALL) who require induction treatment 46%. The rest of subjects were non-lymphoblastic leukemia children (ANLL) who require induction treatment 24%. Eighty-eight percents of children had side effects of chemotherapy. Side effects that were mostly found were nausea and vomiting (52%), fever (39%) and bleeding (30%). Additionally, hemoglobin level was found in moderate level (8.9-9.9 g/dl) which was 46 percents of subjects.

2. Fatigue Experience was composed of fatigue perception, assessment of fatigue, and response to fatigue

2.1 Perception of fatigue was assessed by interviewing with open question therefore children can describe their own perception of fatigue. Most children reported fatigue as Experiencing physical changes such as headache, dizziness, etc. (72%). In additions, 64% of feeling tired and weak, 20% revealed that being unable to do usual activities and there are 2 patients who did not answer the question.

2.2 Sixty-eight percents of samples were in moderate level of fatigue. Mean and median of fatigue level were 5.52 and 5.00. Most samples had much fatigue in the afternoon (62%). Additionally, acute leukemic children mostly reported causes of fatigue that resulted from chemotherapy receiving which were 80 percents of samples. Other causes of fatigue were acute leukemia disease (76%) and nausea and vomiting (52%). Furthermore, the causes of fatigue that children described were much playing, walking, and running.

2.3 Response to fatigue

2.3.1 Physical response to fatigue

The most physical response to fatigue those acute leukemic children reported were muscle fatigue and pain, which were 86 percents. Fifty percents of samples had headache and muscle of limbs weakness. Additionally, the symptoms that acute leukemic children perceived were fasciculation of hand, dizziness, exhausted and hyperpnea.

2.3.2 Mental and emotional response to fatigue

Most of acute leukemic children in this study (70%) expressed anxious and being afraid of their own future. Furthermore, sixty-two percents described the mental and emotional response as easily irritable and thirty percents had response of depression and not concentrated

2.3.3 Behavioral response to fatigue

The behavioral response that sample reported mostly was drowsiness and low spirits which were 74 percents. Sixty-two percents of samples described the response as always sleepy and not active. In addition, there were 60% that would like to lie down and 54% had decrease in to do any activities.

3. Fatigue outcomes interfere with functional status

Acute leukemic children reported that their fatigue perception could interfere the functional status at moderate level.

4. Fatigue management strategies

The management strategy most sample chose to alleviate fatigue was sleeping (100%). The second strategy was talking with friends, siblings or parents, which were 98 percents. Additionally, there were 88 percents reported their fatigue management strategy as eating nutritional food. In case of effectiveness of management strategies, the most effective strategy was sleeping. Meditating, listening to music, and medication were also used to manage with fatigue. Furthermore, the other management strategies were sitting and drinking juice.

### Limitation of the study

1. There were unequal subjects among three hospitals and the sample size of this study was small and not random which limited the generalization of the results to other groups of children with cancer .

2. Open-ended questions using for school-age children can take much time and less detail of answers.

3. During the interview, few parents guided the children to answer the questions, thus affecting the answers of children. A different view of the cancer fatigue experience would undoubtedly be evident if children were interviewed individually.

4. This present study did not have homogeneous sample that were receiving the same cycle of chemotherapy. Most children were in induction phase of chemotherapy while only few were in maintenance and consolidation phase. This would affect fatigue experience of these children and the results might not be applicable to other studies.

#### Recommendations

The findings of the study provide several important implications for the nursing profession including nursing practice, nursing education, and nursing research.

### **Implications for nursing practice**

The findings from this study suggest the following clinical implications for appropriate assessment and management of fatigue for leukemic children receiving chemotherapy.

1. The findings reported here reveal that most subjects reported sleeping as the most effective strategy in reducing fatigue. Since children could benefit from uninterrupted naps and sleep time during hospitalization in order to alleviating fatigue, nurses should promote changes in the environments of treatment settings to promote a more restful environment such as a plan of scheduled activities or allowing time for children to awaken late in the morning. Furthermore, the subjects described other effective strategies that could help decrease fatigue were meditating, listening to music, and taking medications to relieve side effects of chemotherapy. Knowledge of the differing perspectives on what alleviates fatigue in leukemic children provides insight into increased awareness that nurses may need to discuss with each leukemic child and need to reflect input from children when developing clinical interventions.

2. Data obtained from this study suggest that fatigue exists in children who are receiving chemotherapy for cancer. Nurses working with this patient population should incorporate a routine interval assessment of fatigue into the care of these patients, which is a practice guideline that could direct quality patient care.

3. Due to limited ability of school-age children in describing fatigue experience and their concerns related to treatment side effects, parents of these children should be educated about the effects of fatigue on physical, mental, and emotional dimensions of children and aware that fatigue is a symptom warranting intervention.

### **Implications for nursing education**

The concept of fatigue should be taught to nursing students and health care providers at all levels in order to make them understand and realize the important of treatment side effects of fatigue on children receiving treatment for cancer.

### **Implications for nursing research**

1. Future research is required to focus on the outcomes of fatigue management strategies directly such as quality of life, costs, and etc. in children receiving chemotherapy for cancer.

2. The present study needs to be replicated and validated in other ways because the sample was small (50 children) and was not homogeneous in terms of stages of treatment. A larger sample size with the same stage of treatment would enable us to have a more accurate understanding of the fatigue experience in children with cancer.

3. Exploration of the concept of fatigue from the perspectives of parents, staff nurses and doctors along with contributing/alleviating factors should be done to provide the basis for developing interventions for this patient population.

4. Comparison of fatigue experience and management in leukemic adolescents receiving chemotherapy would assist in our understanding of the phenomenon in children and adolescents with cancer. The variety of perspectives we have of a phenomenon, the more comprehensive our understanding of the phenomenon becomes.

5. Continued research of fatigue experience and management in children receiving other type of treatment for cancer such as radiotherapy must be done to compare to the fatigue experience in children receiving chemotherapy.

6. Based on the findings of this present study, further program of research on nursing interventions for alleviating fatigue in children receiving chemotherapy is needed.

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#### **APPENDIX A**

### HUMAN RIGHTS FOR RESERCH POPULATION

# APPENDIX A HUMAN RIGHTS FOR RESERCH POPULATION

### หนังสือยินยอมโดยได้รับการบอกกล่าวและเต็มใจ

#### (Informed Consent Form)

<b>ชื่อโครงการ</b> ประสบการณ์การมีอาการและการจัดการกั	บความอ่อนล้าในผู้ป่วยเด็กโรคมะเร็งเม็ดเลือด
ขาวที่ได้รับการรักษาด้วยยาเคมีบำบัด	
<b>ชื่อผู้วิจัย</b> นางสาวนพรัตน์ ประจิมทิศ	
*ชื่อผู้เข้าร่วมการวิจัย	
อายุ เลขที่เวชระเบียน	
คำยินยอมของผู้เข้าร่วมการวิจัย	
ข้ำพเจ้า นาย/นาง/นางสาว	ซึ่งเป็นผู้ที่มีอำนาจกระทำ
การแทนนาย/นาง/นางสาว/ค.ช./ค.ญ	ได้ทราบรายละเอียดของ
โครงการการวิจัย ตลอดจนประโยชน์ และข้อเสี่ยงที่จะ	ะเกิดขึ้นต่อผู้เข้าร่วมการวิจัยจากผู้วิจัยแล้วอย่าง
ชัดเจนไม่มีสิ่งใดปีดบังซ่อนเร้นและยินยอมให้ทำการวิจ	งัยในโครงการที่มีชื่อข้างต้น และข้าพเจ้ารู้ว่าถ้ามี
ปัญหาหรือข้อสงสัยเกิดขึ้นข้าพเจ้าสามารถสอบถามผู้วิจ	จัยได้ และข้าพเจ้าสามารถไม่ให้ผู้เข้าร่วมการวิจัย
เข้าร่วมโครงการวิจัยนี้เมื่อใดก็ได้ โดยไม่มีผลกระทบต่	อการรักษาที่ข้าพเจ้าพึงได้รับ นอกจากนี้ ผู้วิจัย
จะเก็บข้อมูลเฉพาะเกี่ยวกับตัวข้าพเจ้าเป็นความลับและ	ะจะเปิดเผยได้เฉพาะในรูปที่เป็นสรุปผลการวิจัย
การเปิดเผยข้อมูลเกี่ยวกับตัวข้าพเจ้าต่อหน่วยงานต่าง	ๆ ที่เกี่ยวข้อง กระทำได้เฉพาะกรฉีที่จำเป็นด้วย
เหตุผลทางวิชาการเท่านั้น	
d	2/Cl 0

ลงชื่อ	(ผู้มีอำนาจกระทำการแทน	)
	(พยาน)	
	(พยาน)	
วันที่		

### คำอธิบายของแพทย์หรือผู้วิจัย

ง้าพเจ้าได้อธิบายรายละเอียดของโครงการ ตลอดจนประโยชน์ของการวิจัย รวมทั้งข้อเสี่ยงที่ อาจจะเกิดขึ้นแก่ผู้เข้าร่วมการวิจัยทราบแล้วอย่างชัดเจนโดยไม่มีสิ่งใดปิดบังซ่อนเร้น

> ลงชื่อ.....( แพทย์หรือผู้วิจัย ) .

วันที่.....

ผู้เข้าร่วมการวิจัย หมายถึง ผู้ยินยอมตนให้ทำวิจัย

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A S n	นนพระราม 6 กทม. 10400
The set I	กร. (662) 245-5704, 201-1296 โทรสาร (662) 246-2123
Rajisawountra R	aculty of Medicine, Ramathibodi Hospital, Mahidol University ama VI Road, Bangkok 10400, Thailand el. (662) 245-5704, 201-1296 Fax (662) 246-2123
Documentary Pro	of of Ethical Clearance Committee on Human Rights
Relate	d to Researches Involving Human Subjects
Faculty of Me	dicine, Ramathibodi Hospital, Mahidol University
	0084/20
Title of Project	Symptom Experience and Fatigue Management among
	Leukemic Children Receiving Chemotherapy
Protocol Number	ID 03-46-05
Principal Investigator	Miss.Nopparat Prajimtis
Official Address	Department of Nursing
	Faculty of Medicine, Ramathibodi Hospital
	Mahidol University
The aforemention	aned project has been reviewed and approved by Committe
Juman Rights Relate	d to Researches Involving Human Subjects based on

Signature of Chairman Committee on Human Rights Related to Researches Involving Human Subjects

saplatanaday.

Prof. Krisada Ratana-olarn, M.D., FRCST, FICS.

. . . . .

Signature of Dean

Rater

Prof. Prakit Vathesatogkit, M.D., ABIM., FRCP.

**Date of Approval** 

March 19, 2003

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No.	บันทึกข้อความ		
ส่วนราชการ	คณะแพทยศาสตร์โรงพยาบาลรามาธิบดี	โทร.	i*+ರಿನ ೦ಜೆಡೆಡೆ
ที่	ทม อสออ 19 60 2 วันที่ 19 บีนาคม ๒๕๔๖		
เรื่อง	อนุญาตให้นักศึกษาเก็บข้อมูลเพื่อประกอบการทำวิทยานิพน	ธ์	

เรียน คณบดีบัณฑิตวิทยาลัย มหาวิทยาลัยมหิดล

ตามหนังสืองานบริการการศึกษา สำนักงานบัณฑิตวิทยาลัย สาขาศาลายา มหาวิทยาลัยมหิดถ ที่ ทมodole.oa (ศย)/leda ลงวันที่ led กุมภาพันธ์ ledde แจ้งว่า นางสาวนพรัตน์ ประจิมทิศ นักศึกษาบัณฑิตวิทยาลัย มหาวิทยาลัยมหิดล หลักสูตรปริญญาโท สาขาวิชาการพยาบาลเด็ก คณะแพทยศาสตร์โรงพยาบาลรามาธิบดี มีความประสงค์ขอเก็บข้อมูล เพื่อประกอบการทำวิทยานิพนธ์เรื่อง "ประสบการณ์การมีอาการและการจัดการกับความอ่อนล้าในผู้ ป่วยเด็กโรคมะเร็งที่ได้รับการรักษาด้วยยาเกมีบำบัด" เก็บข้อมูลจากผู้ป่วยเด็กวัยโรคมะเร็งเม็ดเลือด ขาวอายุ ๗–๑๒ ปี ที่เข้ารับการรักษาด้วยยาเกมีบำบัดในหอผู้ป่วย ที่หอผู้ป่วยกุมารเวชกรรม leโรง พยาบาลรามาธิบดี โดยใช้แบบสัมภาษณ์ เป็นเครื่องมือในการวิจัย ตั้งแต่วันที่ ๑ มีนาคม ledde ถึง วันที่ ๑๑ พฤษภาคม ledde ความละเอียดแจ้งแล้ว นั้น

คณะแพทยศาสตร์โรงพยาบาถรามาธิบดี ได้พิจารณาแถ้วไม่ขัดข้อง ยินดีอนุญาตให้ นางสาวนพรัตน์ ประจิมทิศ ทำการเก็บข้อมูลเพื่อประกอบการทำวิทยานิพนธ์ได้ ตั้งแต่บัดนี้จนถึง ๑๐ มิถุนายน ๒๕๔๖ อนึ่งโครงการวิจัยนี้ได้ผ่านการพิจารณาเห็นชอบจากคณะกรรมการจริยธรรม การวิจัยในคนของคณะฯ เอกสารรับรองเลขที่ ๐๐๙๔/๒๕๔๖ (I) ลงวันที่ ๑៩ มีนาคม ๒๕๔๖

จึงเรียนมาเพื่อทราบ

27 Ding.

(ศาสตราจารย์บุญส่ง องก์พิพัฒนกุล) รองคณบคีฝ่ายวิจัย ปฏิบัติราชการแทน คณบคือณะแพทยศาสตร์โรงพยาบาลรามาธิบคี

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Fac. of Grad. Studies, Mahidol Univ.



ตามหนังสือที่อ้างถึง บัณฑิตวิทยาลัย มหาวิทยาลัยมหิดล แจ้งความประสงค์ขอความ อนุเคราะห์ให้ นางสาวนพรัตน์ ประจิมทิศ ซึ่งศึกษาเรื่อง "ประสบการณ์การมีอาการและการจัดการกับความ อ่อนล้ำในผู้ป่วยเด็กโรคมะเร็งที่ได้รับการรักษาด้วยยาเคมีบำบัด" เข้าทำการเก็บข้อมูลจากผู้ป่วยเด็กวัยโรค มะเร็งเม็ดเลือดขาว อายุ 7-12 ปี ที่เข้ารับการรักษาด้วยยาเคมีบำบัดในหอผู้ป่วยของโรงพยาบาลจุฬาลงกรณ์ โดยใช้แบบสัมภาษณ์ ความแจ้งละเอียดแล้ว นั้น

โรงพยาบาลจุฬาลงกรณ์พิจารณาแล้ว ไม่ขัดข้อง ยินดีให้นักสึกษาเข้าทำการเก็บข้อมูลตามที่แจ้ง มาได้ ดิดต่อขอพบผู้ตรวจการพยาบาล ดึกสก ชั้น 16 ในวันที่เก็บข้อมูล

จึงเรียนมาเพื่อทราบ

ขอแสดงความนับถือ

Climits

(รองศาสตราจารย์นายแพทย์คเณศร์ แวววิจิต) รองผู้อำนวยการฯ ฝ่ายวิชาการ ปฏิบัติการแทน ผู้อำนวยการ โรงพย่าบาลจุฬาลงกรณ์

ฝ่ายเลขานุการ โทรศัพท์ 0-2652-4600 ต่อ 3291 โทรสาร 0-256-4368

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#### **APPENDIX B**

### CHARACTERISTICS AND CLINICAL DATA FORM

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#### **APPENDIX B**

#### CHARACTERISTICS AND CLINICAL DATA FORM

## ชุดที่ 1 แบบบันทึกข้อมูลทั่วไป

้ผู้ป่วยเด็กรายที่ HN	มผนก/ร.พ	
ู่ เลขที่แบบสัมภาษณ์	วันที่เกีบข้อมูล	น.

# ส่วนที่ 1 ข้อมูลส่วนบุคคลของผู้ป่วยเด็กโรคมะเร็ง อายุ 7-12 ปี ที่ได้รับการรักษาด้วยยาเคมี บำบัด ( สัมภาษณ์จากผู้ป่วย )

1. เพศ	หญิง	ชาย
2. อายุ	ปี เดือน ( วัน	เดือน ปี เกิด)
3.ระดับการศึกษา	ชั้นประถมศึกษาปีที่	

## ส่วนที่ 2 ข้อมูลเกี่ยวกับโรคและการรักษาของผู้ป่วยเด็กโรคมะเร็ง อายุ 7-12 ปี ที่ได้รับการ รักษาด้วยยาเคมีบำบัด (เวชระเบียน)

1.	การวินิจฉัยโรค			
2.	ได้รับการวินิจฉัยครั้งแรกเมื่อ	.รวมระยะเวลาที่เจ็บป่วย	ปี	เดือน
3.	ระยะของการรักษาด้วยยาเคมีบำบัดในปัจจุบัน			•••••

8. ระดับฮีโมโกลบินในปัจจุบัน ...... g/dl

.

.

# ส่วนที่ 3 ข้อมูลเกี่ยวกับอาการทั่วไปของผู้ป่วยเด็ก ( สังเกตพฤติกรรมของผู้ป่วยในขณะที่ทำการ สัมภาษณ์ )

1. ลักษณะทั่วไปของผู้ป่วยเค็ก

1.1 ท่าของผู้ป่วยเมื่อแรกพบ
 ......ท่านั่ง
 ......ท่านอน
 1.2 สีหน้า
 ......สดชื่น
 ......ไม่สดชื่น

- 2. ลักษณะการเคลื่อนใหว
   ..........ค่อนข้างช้า

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# APPENDIX C FATIGUE INTERVIEW FORM

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### **APPENDIX C**

#### FATIGUE INTERVIEW FORM

#### ชุดที่ 2

#### แบบสัมภาษณ์ความอ่อนล้า

ผู้ป่วยเด็กรายที่	. HNเเผนก/รพ	
้เลขที่แบบสัมภาษณ์	วันที่เก็บข้อมูล	น.

### คำชี้แจง

แบบสัมภาษณ์นี้เป็นแบบสัมภาษณ์ประสบการณ์การมีความอ่อนล้าและผลจากความอ่อน ล้าที่รบกวนภาวะการทำงานของร่างกายตามการรับรู้ของผู้ป่วยเด็กโรคมะเร็งเม็ดเลือดขาวอายุ 7-12 ปี ที่ได้รับการรักษาด้วยยาเคมีบำบัด

ข้อคำถามในแต่ละข้อ เป็นการบรรยายถึงความรู้สึกของกลุ่มตัวอย่างต่อประสบการณ์การมี ความอ่อนล้า และผลจากความอ่อนล้าที่รบกวนภาวะ การทำงานของร่างกาย ตามการรับรู้ของกลุ่ม ตัวอย่าง ในที่นี้ความอ่อนล้า หมายถึง ความรู้สึกอ่อนเพลีย, เหน็ดเหนื่อย หรือไม่มีเรี่ยวแรง ประกอบด้วยข้อกำถามทั้งหมด 11 ข้อ มีทั้งหมด 4 ส่วน ดังนี้

ส่วนที่ 1 การรับรู้เกี่ยวกับความอ่อนล้า

ส่วนที่ 2 การประเมินความอ่อนถ้า

ส่วนที่ 3 การตอบสนองต่อความอ่อนถ้า

ส่วนที่ 4 ผลจากความอ่อนล้ำที่รบกวนภาวะ การทำงานของร่างกาย

ในการสัมภาษณ์ ผู้วิจัยจะอธิบายให้กลุ่มตัวอย่างทราบวิธีการตอบแบบสัมภาษณ์ และอ่าน ข้อคำถามแต่ละข้อให้กลุ่มตัวอย่างเลือกตอบให้ตรงตามความรู้สึกที่สุดจนครบ เมื่อกลุ่มตัวอย่าง เลือกคำตอบแล้ว ให้ทำเครื่องหมาย O ล้อมรอบตัวเลขที่ตรงกับความรู้สึกของกลุ่มตัวอย่าง

#### แบบสัมภาษณ์ความอ่อนล้า

# คำชี้แจง : โปรดทำเครื่องหมาย O ล้อมรอบตัวเลขที่ตรงกับความรู้สึกของกลุ่มตัวอย่าง ส่วนที่ 1 การรับรู้เกี่ยวกับความอ่อนล้า

ใน 24 ชั่วโมง ที่ผ่านมา ความอ่อนล้าที่เกิดขึ้นกับหนู เป็นอย่างไร ( จงอธิบาย )

### ส่วนที่ 2 การประเมินความอ่อนล้า

- 2. หนูรู้สึกว่าความอ่อนล้าที่เกิดขึ้น มีความรุนแรงมากน้อยเพียงใด 2 4 0 1 3 5 6 7 8 9 10 ไม่มี มีความ อ่อนล้ำ ความ มากที่สุด อ่อนล้ำเลย ช่วงเวลาใดของวัน ที่หนูรู้สึกว่า มีความอ่อนล้าเกิดขึ้น 1. เช้า 2. กลางวัน 3. เย็น 4. กลางคืน อื่นๆ (ระบุ)..... 4. หนูรู้สึกว่า ความอ่อนล้าที่เกิดขึ้น มีสาเหตุมาจากอะไร ( สามารถระบุได้มากกว่า 1 ข้อ ) 1. โรคที่หนูเป็นอยู่ 2. การที่หนูต้องมารับการรักษาตัวที่โรงพยาบาล 13. หนูมีอาการท้องเสีย
  - 14. สิ่งอื่นๆ ที่ทำให้หนูมีความรู้สึกอ่อนล้า.....

### ส่วนที่ 3 การตอบสนองต่อความอ่อนล้า

5. เมื่อมีความอ่อนล้ำเกิดขึ้น หนูรู้สึกว่า ร่างกายของหนูเกิดความเปลี่ยนแปลง อย่างไร

			y w
หนูรู้สึกว่า	1.	ศีรษะ	หนักอึง

เมื่อยเนื้อเมื่อยตัว

- 8. มีอาการชาตามปลายมือปลายเท้า
- 9. อื่นๆ.....
- 6. เมื่อมีความอ่อนล้าเกิดขึ้น หนูรู้สึกว่า จิตใจและอารมณ์ของหนูเปลี่ยนแปลงไป อย่างไร
- - ความสามารถ เนการทากจกรรมดางๆ สดสง ทายะ เรามาด เหมือนเดิม เช่น เดินไปห้องน้ำคนเดียวไม่ไหว, รับประทาน อาหารเองไม่ได้
  - 9. อื่นๆ .....

# ส่วนที่ 4 ผลของความอ่อนล้าที่มีต่อการรบกวนภาวะ การทำงานของร่างกาย

10.	หนูรู้สึกว่	่าความ	มอ่อนถ้า <i>ท</i> ิ	เกิดขึ้น	รบกวนก	ารทำกิจ′	วัตรประจ์	ำวันต่าง	ໆ (	ล้แก่ f	າາรอาบน้ำ
	แปรงฟัน	การแ	ต่งตัว การ	รเข้าห้อ <sub>`</sub>	งน้ำ เป็น	ต้น ) ขอ	งหนูมาก	น้อยเพีย	งใด		
	0	1	2	3	4	5	6	7	8	9	10
	ไม่รบกวน										รบกวน
	ເດຍ										ที่สุด
				. y							
11.	หนูรู้สึกว่	่า ควา	เมอ่อนล้า	ที่เกิดขึ้า	่ รบกวเ	าการทำก็	โจกรรมที่	์หนูชอา	เ มากน้อ	ยเพียงใ	ନ
	0	1	2	3	4	5	6	7	8	9	10
	ไม่รบกวน										รบกวน
	ເດຍ										ที่สุด

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# APPENDIX D INTERVIEW FORM FOR FATIGUE MANAGEMENT STRATEGIES IN LEUKEMIC CHILDREN RECEIVING CHEMOTHERAPY

# APPENDIX D INTERVIEW FORM FOR FATIGUE MANAGEMENT STRATEGIES IN LEUKEMIC CHILDREN RECEIVING CHEMOTHERAPY

#### ชุดที่ 3

### แบบสัมภาษณ์กลวิธีการจัดการกับความอ่อนล้ำในผู้ป่วยเด็กโรคมะเร็งเม็ดเลือดขาว ที่ได้รับการรักษาด้วยยาเคมีบำบัด

ผู้ป่วยเด็กรายที่ HN	มผนก/ร.พ	
เลขที่แบบสัมภาษณ์	วันที่เก็บข้อมูล	น.

คำชี้แจง ในข้อคำถามต่อไปนี้ เป็นแบบสัมภาษณ์กลวิธีการจัดการกับความอ่อนล้าในผู้ป่วย
 เด็กโรคมะเร็งเม็ดเลือดขาว อายุ 7-12 ปี ที่ได้รับการรักษาด้วยยาเคมีบำบัด ประกอบด้วยข้อ
 คำถามทั้งหมด15 ข้อ เป็นแบบเลือกตอบ 2 คำตอบ คือ ไม่ได้ทำ และ ทำ โดยผู้วิจัยอธิบายให้
 ผู้ป่วยทราบวิธีการตอบแบบสัมภาษณ์ และอ่านกลวิธีแต่ละวิธี ให้กลุ่มตัวอย่างเลือกตอบ ถ้ากลุ่ม
 ตัวอย่างไม่ได้เลือกทำกิจกรรมใดในการจัดการกับความอ่อนล้า ให้ทำเครื่องหมาย √ ลงในช่อง "
 ไม่ได้ทำ " ถ้ากลุ่มตัวอย่างเลือกทำกิจกรรมใดในการจัดการกับความอ่อนล้า ให้ทำ
 เครื่องหมาย √ ลงในช่อง "ทำ" และให้บอกผลของการใช้กลวิธีนั้นๆ ในการช่วยบรรเทา
 ความอ่อนล้าที่เกิดขึ้นกับกลุ่มตัวอย่างได้มากน้อยเพียงใด โดยมีเกณฑ์ในการเลือกตอบดังนี้

ไม่ได้ทำหมายถึงหนูไม่ได้ทำกิจกรรมในการช่วยบรรเทาความอ่อนล้าทำหมายถึงหนูทำกิจกรรมในการช่วยบรรเทาความอ่อนล้าไม่ได้เลยหมายถึงกิจกรรมที่ทำไม่ได้เลยหมายถึงกิจกรรมที่ทำไม่กลางหมายถึงกิจกรรมที่ทำช่วยบรรเทาความอ่อนล้าได้ปานกลางมากที่สุดหมายถึงกิจกรรมที่ทำ

กิจกรรมที่ทำเพื่อบรรเทา	ไม่ได้ทำ	ຳຳ	ประสิทธิภาพของกลวิธีการจัดการความอ่อนล้า			
ความอ่อนล้ำที่เกิดขึ้น			ไม่ได้เลย	ปานกลาง	มากที่สุด	
			(0)	(1)	(2)	
1. นอนหลับ						
2. งีบหลับหรือหลับในช่วงสั้นๆ						
3. หยุดทำกิจกรรมที่กำลังทำ						
14. ใช้ยาลดอาการอื่นๆ เช่น คลื่นไส้						
อาเจียน, อาการเจ็บแผลในปาก						
เป็นต้น ระบุ						
15. อื่นๆ ระบุได้มากกว่า 1 กิจกรรม						

### แบบสัมภาษณ์กลวิธีการจัดการกับความอ่อนล้า

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# APPENDIX E LIST OF EXPERTS

### APPENDIX E

#### LIST OF EXPERTS

- Associate Professor Pornsri Sriussadaporn Department of Pediatric Nursing Faculty of Nursing, Mahidol University
- Associate Professor Sasitorn Wannapong Department of Pediatric Nursing Faculty of Nursing, Srinakarinwirot University
- Assistant Professor Doctor Seepan Kantawang Department of Pediatric Nursing Faculty of Nursing, Chiangmai University
- Assistant Professor Aroonsri Tachashong
   Department of Nursing
   Faculty of Medicine, Ramathibodi Hospital, Mahidol University
- Miss Krisana Kramseang Newborn and Pediatric ward, King Chulalongkorn Memorial Hospital

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#### BIOGRAPHY

NAME	Miss Nopparat Prajimtis
DATE OF BIRTH	14 March, 1977
PLACE OF BIRTH	Chai Nat, Thailand
INSTITUTION ATTEND	Boromarajonani College of Nursing,
	Chai Nat, 1995- 1999:Bachelor of
	Nursing Science
	Mahidol University, 2001-2004: Master
	of Nursing Science (Pediatric Nursing)
POSITION AND OFFICE	1999-Present, Boromarajonani College of
	Nursing, Chai Nat, Thailand
	Position: Registered Nurse 4